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## INTRODUCTION

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This handbook is designed for anyone in public health who recognizes the need to learn more directly from the people in his or her community. Focus groups can put you in touch with these people.

The heart of this handbook is what we learned in 27 focus groups with people representing populations in the United States that are disproportionately affected by diabetes. Recognizing that various cultural and demographic factors influence the effectiveness—or cause the failure—of health communication programs, the Centers for Disease Control and Prevention (CDC) embarked on a nationwide project in 1994 to learn more about how people living with diabetes view their disease. Nine focus groups were conducted with American Indian people and six each with African American, Hispanic/Latino, and Asian American people, including several subgroups of these major populations (e.g., several American Indian tribes). One of our guiding principles was to “honor the stories” we were privileged to hear (Casey, 1998). We learned a lot, not only about how people live with diabetes, but also about how to conduct research more effectively. It is our hope that you will be able to adapt the lessons we learned in our study about people themselves *and* about how to conduct effective research in your own community.

One of the most important lessons we learned is that research should never be viewed simply as a process of gathering information. From our study, we were reminded of our ethical obligations to share information as well as to receive it, and along the way, discovered the benefits and rewards of negotiating a balance between “giving and getting.” (Many people who have participated in research projects, especially those in minority populations, believe that they have received no benefit from their participation.) The “gifts” in this study included information and cultural sharing, the chance to build partnerships between the research community and the participants’ communities, and the tangible monetary payment for participation.

To illustrate this point, in section 3 we suggest how you may be able to give back to the communities in which you conduct focus group research. Each example is enclosed in a circle, which both represents the continuous process of giving and receiving and is the heart of a lesson we learned while conducting groups of American Indians. The tradition within many tribes is to hold meetings with participants seated in a circular configuration, to eliminate a spatial sense of hierarchy. We believe that the researcher-participant relationship should also be free of hierarchy and should be viewed as an equal partnership, mutually beneficial to all.

Will you want to do research after reading this handbook? We hope so. There are questions to answer in and about each unique community, and there is no substitute for seeing the faces and hearing the voices of community members. We wish you success in your endeavors to explore important public health questions with your community and hope that our findings make a valuable contribution to your understanding of diabetes and your ability to communicate more effectively.



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# ***ORGANIZATION OF THIS HANDBOOK***

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This handbook has five sections:

## **1. Why This Handbook Was Written**

The burden of diabetes need not be as great as it is. Effective health communication supported by sound research is one tool available to public health professionals and program planners who work to ease this burden. This handbook is designed to help health professionals carry out focus group research that can lead to a better understanding of—and, ultimately, better communication with—the communities with which they work. Special attention is paid to conducting focus groups with a limited budget and among racial/ethnic groups that are disproportionately affected by diabetes.

## **2. Lessons Learned About Living with Diabetes**

In this section, we share what our research revealed about what it's like to live with diabetes in various communities and about cultural aspects of communicating information on diabetes. The findings from our background literature search and focus group study are covered separately for American Indians, African Americans, Hispanics/Latinos, and Asian Americans.

## **3. Conducting Effective Focus Groups**

This is the handbook's largest section. We set out to learn how cultural and other characteristics and circumstances affect people's perceptions about diabetes. Along the way, we also learned a great deal about the importance of taking culture into account in conducting focus groups. This section offers a step-by-step plan for preparing for, convening, conducting, and assessing the findings from a focus group study. We share what we learned over the course of our 27-group study with American Indian, African American, Hispanic/Latino, and Asian American participants.

#### **4. Resources on Focus Groups for Further Reading**

This section lists print and electronic resources we found useful and contacts for more information.

#### **5. Articles Used for Background Research in CDC's Diabetes Prevention Marketing Study**

In this section, we list more than 80 articles that we consulted for the Diabetes Prevention Marketing Study. The articles are arranged by topic area.

#### **Appendices**

The five appendices include the focus group screener and discussion guide and the executive summary of the Diabetes Prevention Marketing Study.



# 1. WHY THIS HANDBOOK WAS WRITTEN

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*If the CDC [Centers for Disease Control and Prevention] is to maintain the reputation it now enjoys, it will be because in everything we do, as the basis for every program decision, we are willing to see faces.*

—William H. Foege, former director, CDC

\* \* \* \* \*

Because you decided to explore this handbook, chances are you already know quite a lot about diabetes. If you work with people who have diabetes, you have seen its impact on their lives and on their families and communities. Many people are greatly challenged by the treatment plans they must follow to avoid the terrible toll of complications such as blindness, amputation, kidney failure, and adverse outcomes of pregnancy.

You are probably aware of these alarming statistics (CDC, 1997):

- ◆ In 1997, about 10.3 million people in the United States had been diagnosed with diabetes--a sixfold increase over the past four decades--and another 5.4 million people had undiagnosed diabetes.
- ◆ In 1992, an estimated \$92 billion in direct and indirect costs was spent on diabetes.
- ◆ In 1995, approximately 67,000 diabetes-related amputations were performed.
- ◆ In the United States, African Americans, Hispanics/Latinos, and American Indians have higher rates of diabetes than do others. A number of studies have also shown increased rates of the disease among certain Asian and Pacific Islander populations.

No doubt, you are also aware that the burden of diabetes need not be as great as it is. Widespread clinical and public health prevention programs can deter the onset, development, and progression of this condition.

How can we do a better job of linking what we know with better outcomes for people at risk for or living with diabetes? How can we work more effectively to relieve the burden of diabetes among those populations disproportionately affected? These questions were the

## **The Link Between Understanding Living with Diabetes and Effective Health Communication**

basis of the Diabetes Prevention Marketing Study, begun in 1994 under the sponsorship of the Centers for Disease Control and Prevention (CDC). Three issues guided that study and this handbook: (1) the link between understanding the challenges of living with diabetes and effective health communication, (2) the role of cultural competence in health communication, and (3) a desire to share the lessons we learned.

*Health communication is the crafting and delivery of messages and strategies, based on consumer research, to promote the health of individuals and communities.*

—William L. Roper, former director, CDC

\* \* \* \* \*

What is it like for people to live with diabetes? What is it like for their families? What role do their communities play? These should be central questions for health professionals. At CDC, health communication is grounded in a social marketing framework that places the *consumer* at the center of all we do. The voices of people in communities drive the development of ideas and messages. To communicate effectively, we must learn about what our audiences want and need, what barriers they face and what motivates them, what support they need, and what they already believe and do. Finding that information requires research.

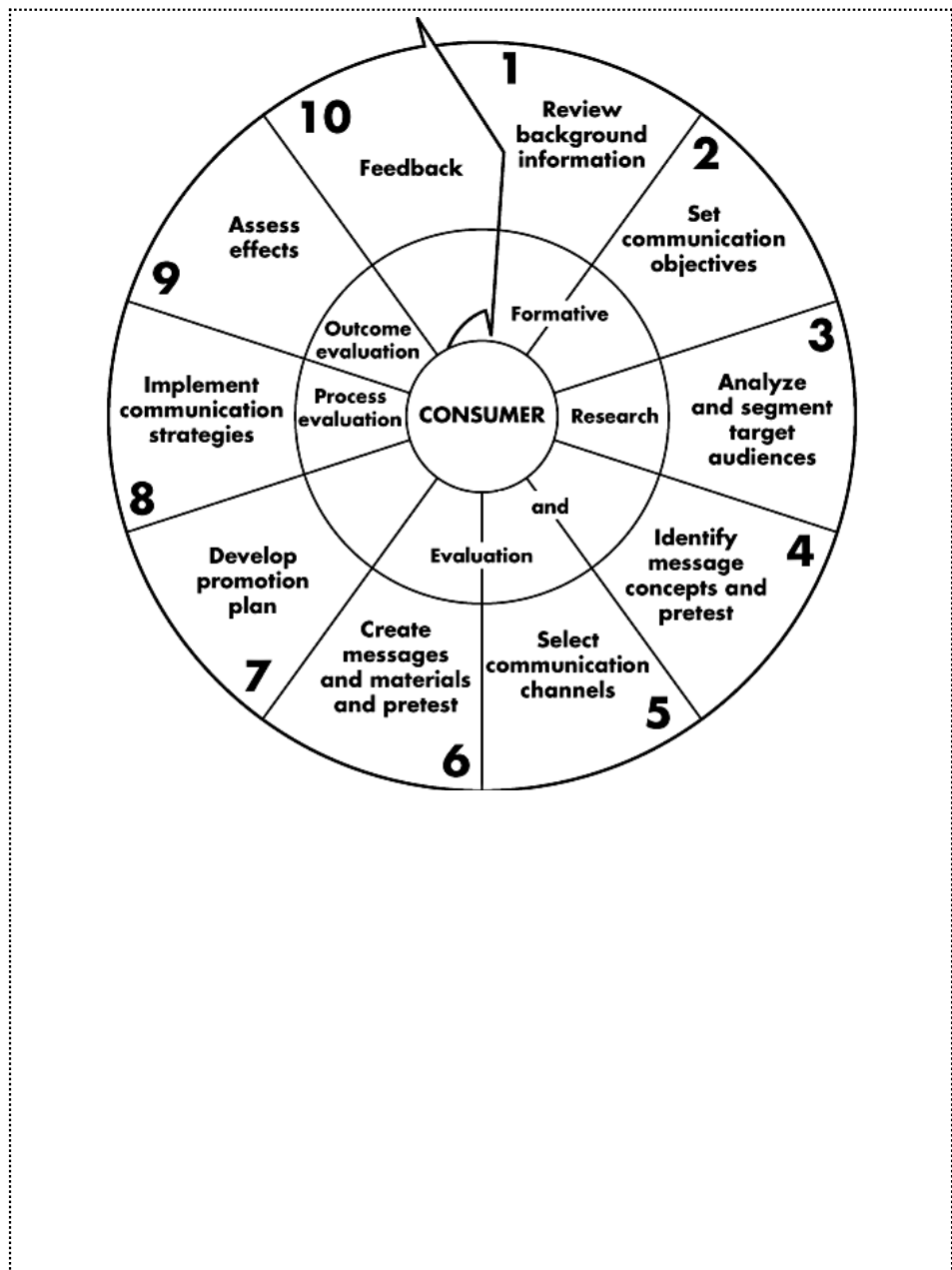
We use research throughout the health communication process, as is apparent in what we refer to as the Health Communication Wheel (shown in Exhibit 1). In this model, the placement of evaluation within the inner circle emphasizes the importance of assessing the needs of an intended audience. The model is circular in shape to indicate that the process is ongoing. In keeping with the model, researchers should conduct formative evaluation to test materials or learn more about audiences, as the Diabetes Prevention Marketing Study did. Health promotion plans are then implemented and evaluated, and the findings help ensure that future health programs are designed more effectively.

Focus groups are a research method that can be used at any of several points in the model. A focus group study involves a series

of discussions that are guided by preselected questions; are facilitated by a trained moderator; and are conducted among small, homogeneous groups of people. Consider how your program might use focus group studies. For example, you could use the method to help you profile your audience or test concepts and messages you have developed. Or, you could use it to help gauge reactions to a program or determine how it can be improved. The method is discussed in depth in section 3 of this handbook.

**Exhibit 1**

**Health  
Communication  
Wheel**



## The Role of Cultural Competence in Health Communication

*If communities and cultural barriers are not appropriately identified and accommodated, then we will ultimately fail in attempts to curb the impact of this most debilitating disease.*

—J.R. Gavin and N. Goodwin in  
*Diabetes Care*, 1990

\* \* \* \* \*

We live in an increasingly diverse society. If effective prevention programs are based on understanding people and their environment, then learning more about the role of cultural factors in health communication is imperative. This understanding is vital because cultural factors are an integral aspect of life and health care for a large proportion of the people living with and most at risk for diabetes.

### Culture can affect

- ◆ What symptoms a person considers to be a problem.
- ◆ Comfort level with the way health care providers communicate.
- ◆ Belief that diabetes can be prevented through exercise and diet.
- ◆ An individual's desire to keep an illness confidential.
- ◆ Beliefs about the cause of illness (and perhaps about the cure as well).
- ◆ Tendencies toward stoicism or dramatic reactions to discomfort or pain.
- ◆ Trust or distrust of medical advice or procedures.
- ◆ Types of social support provided by family and community.
- ◆ Perception of the best method of treatment.

Cultural competence has been defined as “a set of academic and interpersonal skills that allow individuals to increase their understanding and appreciation of cultural differences and similarities within, among, and between groups” (U.S. Dept. Of Health and Human Services, 1992, p. vi). For health professionals, learning more about the communities with which they work can be a part of their growth in cultural competence.

Being responsible and responsive toward varying cultural needs is discussed in the literature as a set of components or a process of

stages. For example, components might include a commitment to cultural competence, awareness and acceptance of differences among cultures, and self-awareness (Ronnau 1994). Other researchers offer the components as action statements, such as know yourself, keep an open mind, respect differences among peoples, be willing to learn, learn to communicate effectively, don't judge, and be resourceful and creative (Grossman 1994).

Similarly, the stages, known by a variety of names, tend to follow a similar progression: (1) cultural sensitivity or awareness (being conscious of the nuances of other cultures *and* one's own culture) leads to (2) cultural knowledge (understanding cultural differences, seeking accurate information about a cultural group), which results in (3) cultural competence (the fusing of sensitivity and knowledge with behaviors that enhance interaction among persons from varied cultures) (Kavanagh and Kennedy 1992; Torres 1993).

Cultural competence is vital because none of our messages about diabetes and self-care strategies will make a difference if

- ◆ The information is inconsistent with important cultural practices, traditions, or beliefs.
- ◆ The information proposes actions that are impractical or impossible given the adverse economic circumstances for a significant portion of populations affected by diabetes.
- ◆ The information is provided at a level that exceeds the audience's reading skill or in a language that the audience does not speak at all, read at all, or both.
- ◆ The health care practitioners and educators are unaware or unresponsive to how language, religion, dietary practices, and a host of other cultural factors influence diabetes care and communication.

## Why Focus Groups?

*Through listening, the would-be health communicator becomes educated by the community. What follows, then, can be a partnership in which mutual sharing (dialogue) and respect become the model of communication. The sharing approach to communication fosters an interactive dialectic in which communities can empower themselves. . . .*

—William R. Brieger, in  
*The Nation's Health*, February 1997

\* \* \* \* \*

Several research methods are available to public health professionals working to learn more about their communities. The methods include telephone and mail surveys, individual interviews, and statistical analysis of epidemiologic data. Focus group research is a unique and important tool. Focus groups have been used for several decades, usually to obtain opinions about and reactions to consumer products and services or advertising or marketing campaigns. But focus groups also can be very useful for health communication.

The value of this research method lies in the ability of focus group discussions to give the public health community a chance to explore issues with participants in great depth. Properly planned and moderated groups can reveal different, often more hidden, information than can other research methods.

Focus groups are ideal for exploring issues that a person could not answer quickly and easily by phone or in writing. Discussion is a more effective vehicle for thoughtfully exploring such topics. Also, more details about responses can be observed in focus groups than with some other methods (e.g., whether participants fervently believe in an issue or simply agree with it without a commitment). Moreover, in a group setting, one person's comments can stimulate wider-ranging discussion among the other participants. And participants in a focus group may raise topics that focus group organizers did not even know to ask about. Finally, perhaps surprisingly, research shows that participants often feel more comfortable discussing potentially embarrassing health problems in a group setting with others who share the problem than they do discussing the problems one-on-one in a private interview. The ability of focus groups to discover participants' true thoughts and feelings led one market researcher to characterize focus groups as "eyes and ears to the real world" (Feig 1996).

Focus groups can successfully explore these topics, among others:

- ◆ People's understanding of what diabetes *is* and the role culture plays in how they manage it.
- ◆ People's underlying reasons for particular health care decisions.
- ◆ People's emotions about having a chronic condition and how those emotions evolved from the time diabetes was diagnosed to the present day.
- ◆ The complex roles families can play in the patient's health care.
- ◆ Myths about health issues, where they are learned, and why they are believed.
- ◆ The health-related barriers people face every day and what can motivate them to overcome the barriers.
- ◆ How meaningful a campaign concept or message might be to a target audience and how it could be improved.

Like other research methods, the very aspects of focus groups that make them so valuable also limit them in some ways. The main limitation is that focus group participants are generally selected from a convenience sample (persons who share specific characteristics) rather than a random sample. The findings therefore are not generalizable to a large population. Also, the small number of people who participate in a focus group session—discussions work best with fewer people—keeps sample sizes too small for findings to be generalizable. Focus group findings can therefore be characterized as descriptive rather than definitive. The findings are useful as guidance, but they cannot be communicated in statements such as “American teenage girls believe X” or “Older Hispanic/Latino men see their role in the family as Y.” Rather, findings must be stated in terms of what *study participants*—not an entire population—expressed. A focus group study may indicate participants’ views about what direction would be most fruitful for a campaign. Or, such a study may bring to light the reasons some people avoid a local clinic, so that those problems can be addressed. Or, a health department may gain insights about how some people might be able to progress from denial of their diabetes to acceptance and effective management.

Traditionally, focus groups have the following features:

- ◆ **About eight to 10 participants who are representative of a particular audience** (e.g., 10 women who have experienced gestational diabetes). Characteristics such as race, income, occupation, or a particular belief or opinion about something may also be important. Participants are usually recruited by telephone by a professional focus group recruiter.
- ◆ **A trained professional moderator** who, using a discussion guide, introduces predetermined questions, topics, or materials to promote interactive discussion with participants.
- ◆ **A focus group facility** equipped with recording equipment and a one-way mirror, behind which observers may sit.
- ◆ **A duration of about 90–120 minutes.**
- ◆ **Refreshments and nominal payment** to encourage participants to attend and to show appreciation to them for contributing their opinions.

However these traditional features of a focus group must often be modified to suit unique circumstances or participants, for example, to

- ◆ Reach people in communities or neighborhoods that lack commercial focus group facilities.
- ◆ Recruit people to participate who may not be reachable by telephone.
- ◆ Invite people who do not have transportation.
- ◆ Talk with people who may not speak English.
- ◆ Conduct research with very limited resources.

There is a science to conducting research through focus groups. Every aspect of the process of convening groups, composing discussion guides, and analyzing results includes prescribed steps. This handbook touches only the tip of the iceberg. If after reading this handbook you would like to read more about focus groups, excellent references are available. We suggest further reading in

section 4 of this handbook, which contains an annotated bibliography of print and electronic sources of information.



## Summary

- ◆ This handbook was written to communicate the lessons learned during CDC's Diabetes Prevention Marketing Study. It is intended to help persons who wish to conduct similar focus group research in their own communities.
- ◆ CDC's Health Communication Wheel and the concept of cultural competence are keys to conducting effective research in the context presented by this handbook.
- ◆ Focus groups are a valuable research tool for exploring topics that require in-depth discussion to be understood (e.g., the complex roles that families play in self-care, how meaningful a campaign concept or message is to members of the target audience).
- ◆ Focus groups have some limitations, in particular, the inability to apply the findings to a larger population.



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## ***1. Why This Handbook Was Written***

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## 2. *LESSONS LEARNED ABOUT LIVING WITH DIABETES*

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*To be successful in community work  
we need a good sense of history, humility,  
and a deep respect for the people with whom we work.*

—Freire, 1988

\* \* \* \* \*

Throughout this handbook, you will read highlights of what we learned in the course of the Diabetes Prevention Marketing Study. In this section, we provide some special insights. We hope you will be able to use these to compare with research you have already completed, to consider topics or issues you might want to explore locally, and to otherwise help you conduct your own focus group research to strengthen your understanding of people living with diabetes in your community.

### **Lessons Learned from the Literature, Expert Interviews, and People Living with Diabetes**

As part of our preparation for the focus group study, we conducted a literature review of more than 100 articles and studies and interviewed 24 experts on the four population groups for this study: American Indians, African Americans, Hispanics/Latinos, and Asian Americans. Many of these articles and interviewees addressed health communication in general rather than diabetes specifically, but they nonetheless provided useful background that helped us define the purpose and methods for our focus group research. For example, insights we gained from the literature review made us more aware of the barriers to care that many people with diabetes face and reminded us that many of these barriers (e.g., limited transportation) might also influence various aspects of the focus group research. The literature also stimulated key questions for our focus groups about issues such as the influence of family support, the meaning in different languages of words and terms commonly used in diabetes communication efforts, and how a patient's relationships with medical personnel affect attitudes toward disease and self-care practices. Two sample findings and a few examples of each follow.

**Certain barriers to health care, many of which are interrelated, are common to historically disadvantaged people—who are**

**disproportionately represented among people with diabetes—and to the cultures we wanted to learn more about.**

**For example:**

- ◆ Low income/poverty and the need to cope with corresponding stress and difficulties
- ◆ Lack of health insurance
- ◆ Limited knowledge of health care and entitlement systems
- ◆ Distrust of those systems and of some health care providers
- ◆ A native language other than English
- ◆ Low literacy skills
- ◆ Longer distance to care but limited or no transportation
- ◆ Reliance on emergency room and public hospitals, limiting care to acute episodes
- ◆ Low adherence to prescribed regimens due to the cost of supplies and treatment

**Words and terms related to diabetes and its treatment have different meanings in different languages and cultures. Below are some examples.**

- ◆ A study involving Mexican American women reported respondents' understanding of *sugar diabetes* to mean both the complications of diabetes (e.g., blindness, amputations) *and* table sugar in the blood (Luyas 1991). For some Asians, *sugar* implied only table sugar—not other components of the diet that contain sucrose, such as honey-sweetened foods and sweet teas (Burden, Samanta, and Rahman 1988).
- ◆ For many Hispanics/Latinos, the term *diet* has negative connotations. In one study, Hispanic/Latino women made a distinction between *diet food*, also called American food, and Spanish or Mexican food (Hendricks and Hass 1991).
- ◆ In one study involving older African American women in the South, *fresh* also implied tasteless (Lieberman, personal interview).

In conducting the literature review and interviews, we concentrated on common perceptions about illness and diabetes among each of the four target populations. We found a wealth of knowledge and research that helped illuminate some perceptions held by many members of the target populations. The literature review and interviews also suggested some general findings about specific racial/ethnic groups and guided our decisions about which questions to ask and the most appropriate ways to conduct the focus group sessions.

Most of what the focus group participants told us supported what we had learned from the expert interviews and literature review. However, focus group participants also brought some new perspectives, new language, and valuable insights that our other sources had not mentioned. The ways in which participants added to knowledge we had gained from secondary sources highlight why you should consider conducting groups in your community. Simply put, the groups you convene may yield findings that are different from ours. In fact, the specialized information you can gain about your community may be key to successful communication initiatives. So, what we learned should be a starting place for you rather than a substitute for conducting focus groups in your own locale. In addition, by conducting focus groups, you can communicate to community members that you want to hear from them.

Findings related to each of the four racial/ethnic groups on which we concentrated are shown in Exhibits 2 through 5. Each exhibit lists major findings from the interviews and literature that are related to the particular population, followed by especially interesting or relevant focus group findings that were not discussed in either the interviews or the literature. The findings from the literature review are stated as global findings; by contrast, the findings from the focus groups are typically expressed as the views of some or all of the participants. As the focus group findings help to demonstrate, enormous individual diversity exists even among a small group of people who share a language and culture.

The text of the executive summary on findings from the Diabetes Prevention Marketing Study is included in this handbook as Appendix A.

**Exhibit 2. Perceptions about diabetes among American Indian populations**

- Some American Indians see diabetes as coming from the white man and the loss of traditional lifestyles. Diabetes disrupts the *hohzoni*, or internal balance of being (Hagey 1984, 1989; Huttlinger et al. 1992; Lang 1989; MacDonald, Shah, and Campbell 1990; Newman, Hollevoet, and Frohlich 1993).
- Persons who get involved in the white man's world are thought to be more susceptible to diabetes (Hagey 1984).
- Diabetes can be caused, many think, by a buildup of sugar, family stress, being overweight, genetics, drinking alcohol, lack of fresh food, and not living right (Lang 1989; Newman 1993).
- Diabetes is often considered a fact of life. Attitudes are often fatalistic (Doughty 1994; Hagey 1984).
- Diabetes is viewed by some as a lack of spiritual strength that must be resolved by individuals. Punishment and stigmatization may occur (Hagey 1984; Judkins 1978).
- Native healing rituals or treatment are sometimes sought for relief (Lang 1989; Newman 1993).

We conducted nine groups with American Indian men and women in Minneapolis and at tribal reservations in Montana and Wyoming. The following findings are from our transcripts of the groups, which provide a record of similarities and differences among participants at different reservations and between men and women.

- Many participants expressed intense feelings of shame about having diabetes. They felt that they would be stigmatized in their communities if other people found out. This perception seemed quite prevalent among the men.
- Some of the women who lived on a reservation bemoaned the fact that although one of the best ways for them to exercise is walking, they fear attack from stray dogs.
- Although participants want to follow a diet regimen that will help control their diabetes, they said that foods such as fresh fruits and vegetables and leaner cuts of meat are not affordable. Government commodities—often high in fat and sugars—constitute a significant portion of their diet.
- Some participants expressed a longing for continuity in their health care. They said that through the Indian Health Service, they may see a particular doctor only once or twice and are unable to establish a longer-term relationship.
- Some participants who use nontraditional treatment methods for diabetes said that they rarely tell their doctors for fear of being ridiculed. Others do not share the information with doctors because the methods are considered sacred.

**Exhibit 3. Perceptions about diabetes among African American populations**

- The idea of preventive health measures can run counter to a “strong sense of the present” that is part of the culture for many African Americans (Anderson et al. 1991).
- A cultural acceptance of overweight may result from, and perhaps contribute to, the prevalence of obesity among older women (Kumanyika and Ewart 1990).
- In one study, family and friends’ support for treatment plans was a positive force for women but decreased the likelihood of adherence to plans for men (Uzoma and Feldman 1989).
- Younger people tend to be less open about diabetes than older people, who have more peers with the disease (Reid 1992).
- Older people with diabetes tend to rely less on folk and popular sectors of the health care system and more on professional care than do younger people (Reid 1992).
- One study showed that older patients with higher levels of self-efficacy were most likely to adhere to an insulin regimen (Uzoma and Feldman 1989).

Six groups were conducted with African American men and women in Chicago, Houston, and Ashburn (Georgia). These were among the themes expressed by these groups.

- No one felt prepared for the life changes that followed the diagnosis of diabetes.
- Participants attributed the high incidence of diabetes to stress in the community, lack of information, a preponderance of other serious illnesses, and dietary preferences. Some participants described a perception of stress related to social ills, citing crime, being laid off work, lack of transportation, lack of resources, AIDS, racism, and lack of communication between family members.
- Participants in all groups expressed concerns about the financial burden of diabetes. Many participants voiced appreciation for health care providers who were flexible about payment for services.
- Many sources of information were mentioned, including print material from health care providers (hospitals, clinics, doctors, dietitians); workshops, classes, and other presentations at hospitals and clinics; and the American Diabetes Association. In general, participants were satisfied with the information they receive but said that it needs to be disseminated more widely among young adults.
- Participants did not express a strong preference for African American health care providers, but some said that providers’ knowledge of the cultural significance of diet would be useful.
- Several participants said that diabetes does not get the same attention within the African American community as do cancer, high blood pressure, and stroke.

**Exhibit 4. Perceptions about diabetes among Hispanic/Latino populations**

- Illness results from disharmony in the body (Reinert 1986; Zaldivar and Smolowitz 1994).
- Illness is usually seen as a state of discomfort. The absence of symptoms for early diabetes therefore makes it less of a concern (Reinert 1986).
- Disease, pain, and suffering are viewed as determined by God and therefore are to be endured as punishment for wrongdoing. Long-term illness is part of one's destiny and is to be endured stoically (Adams, Briones, and Rentfro 1992; Hall 1986; Hendricks and Hass 1991; Martinez 1993; Reinert 1986; Schwab, Meyer, and Merrell 1994; Zaldivar and Smolowitz 1994).
- There is a strong correlation between low socioeconomic status, limited acculturation, old age, and belief in folk medicine (Reinert 1986).
- There is some use of herbalists (*yerberos*) and masseuses (*sobaderos*) for treating diabetes (Adams, Briones, and Rentfro 1992; Reinert 1986; Zonszein 1993).
- Diabetes is believed to be caused by too much sweet food and accumulated sugar in the blood, an inherited condition related to being overweight, the cumulative effect of interacting experiences since childhood (including stress), and sugar-thickened blood that interferes with circulation (Zaldivar 1994).
- In Hispanic/Latino families, women make the decision about when to turn to outside help (Davidson 1991; Reinert 1986).
- To some, insulin is a last resort. They believe that if they need insulin, they are going to die soon or lose their eyesight (Davidson 1991).
- Exercise is associated with expensive health clubs, the work of lower classes, or both. It is not believed to have therapeutic benefits and is seen as appropriate principally for men and young people (Hall 1986; Urdaneta and Krehbiel 1989).

Six groups were conducted (in Spanish) in Los Angeles and New York City with Hispanic/Latino men and women originally from Mexico, Puerto Rico, Central America, and the Dominican Republic. The following are examples of themes that were expressed by these focus groups.

- Several participants said they typically forgo buying needed medication, glucose testing strips, or both until they can afford them or a family member buys them.
- Among male participants' concerns about the complications of diabetes, one of the most important is the fear of sexual dysfunction. Many admitted that their experience with impotence negatively affected their self-esteem.
- Some participants said they believe that the onset of diabetes results from a strong emotional reaction to a good or bad event (e.g., winning the lottery, being robbed, witnessing a suicide).
- Some participants said they feel inhibited about asking their physicians diabetes-related questions because they feel ashamed of taking up too much of the doctors' time and are afraid that the doctors will become angry.
- Most participants said that their community offers them little support in managing their diabetes.

**Exhibit 5. Perceptions about diabetes among Asian American populations**

Literature review and expert interview findings
<p>There was little specific information about diabetes, but findings about general health beliefs were striking.</p> <ul style="list-style-type: none"> <li>• The hot/cold, male/female (or yin/yang) system concerning foods and illness is influential (Hawthorne, Meool, and Tomlinson 1993; Randall-David 1989).</li> <li>• The hope for cures can take precedence over acceptance of long-term management (Burden, Samanta, and Rahman 1988).</li> <li>• There is some use of amulets and religious papers to ward off evil and as medications (Hawthorne, Meool, and Tomlinson 1993).</li> <li>• A reluctance to obtain help for “minor” problems and a stoic attitude about symptoms exist (Hendricks and Hass 1991).</li> <li>• Some believe that Western medications are too strong for small bodies, so some patients adjust dosages at times (Waxler-Morrison, Anderson, and Richardson 1990).</li> <li>• Some believe that once symptoms are relieved, medication can be discontinued (Hendricks and Hass 1991; Waxler-Morrison, Anderson, and Richardson 1990).</li> <li>• In some cultures (e.g., Asian Indian), treatment may be withheld from a young woman or her condition may be concealed so as not to impede her ability to find a suitable husband (Burden, Samanta, and Rahman 1988).</li> <li>• Deference is shown to health care providers. Patients may withhold questions out of concern that they might imply that a practitioner lacks expertise (Kittler and Sucher 1990).</li> </ul>
Focus group findings
<p>Six groups were conducted with Asian participants. In Los Angeles, groups were convened with Korean men and women (and conducted in Korean) as well as with Filipino (in Tagalog) and Vietnamese (in Vietnamese) men and women. Two groups were conducted with Chinese participants in New York (one in Mandarin and one in Cantonese). Some common themes voiced in the focus groups included the following.</p> <ul style="list-style-type: none"> <li>• Women were concerned about injections.</li> <li>• Some believed that doctors try to control patients by doling out information a little at a time and discounting the value of non-Western treatment.</li> <li>• Participants said that diabetes is caused by a combination of factors, including intense emotional stress, consumption of sweets, and hereditary disposition.</li> <li>• Participants said that illness is more manageable if the mind is peaceful and positive.</li> <li>• Participants were very worried that their illness would make them dependent on others.</li> </ul>



**Summary**

- ◆ A literature review and interviews with experts provided important guidance to the Diabetes Prevention Marketing Study.
- ◆ For the most part, the focus groups echoed these findings. The groups also revealed new and unexpected information.

- ◆ By conducting focus groups in your community, you can gain new information specific to your locale and see the challenges of living with diabetes through the eyes of community members.



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## ***2. Lessons Learned About Living with Diabetes***

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### 3. *CONDUCTING EFFECTIVE FOCUS GROUPS*

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In this section, we walk step-by-step through the basics of setting up focus groups and point out some important implications of focus group research of participants' cultural or racial backgrounds, socioeconomic circumstances, language, and clinical conditions like diabetes. Many of the most critical lessons we learned are highlighted in boxes. Suggestions for ways you can give something back to the communities with which you work are shown in circles.

This section follows the typical sequence of activities for a focus group study. For the most part, we followed this sequence for the Diabetes Prevention Marketing Study. Keep in mind that these are flexible guidelines, not rules, and feel free to adapt them to make the most of your research resources.

#### **Step 1: Developing a Plan**

- ◆ What do you want to learn? Defining your purpose and approach.
- ◆ Put it in writing.
- ◆ Who should help? Developing partnerships.
- ◆ Who else should be on the team? Choosing moderators and translators.
- ◆ Who is your audience? Defining the composition and number of groups for your study.

#### **Step 2: Determining Where and When to Schedule the Groups**

- ◆ Where can you hold groups? Selecting places.
- ◆ What times are good for groups? Setting a schedule.

#### **Step 3: Recruiting Focus Group Participants**

- ◆ Where is everyone? Finding people who may be qualified.
- ◆ How do you recruit them? Assuring the right people are invited.
- ◆ Will they come? Persuading people to show up.

**Step 4: Developing the Discussion Guide and Other Materials**

- ◆ How do you ask the right questions? Components of a guide.

**Step 5: Logistical Details and Procedures**

- ◆ What to eat? Planning refreshments.
- ◆ Are you ready? Setting up the facility.
- ◆ How will you remember everything? Recording and note taking.

**Step 6: Interpreting the Results**

- ◆ What have you learned? Figuring it out.

**Step 1:  
Developing a Plan**

Think about what you want to learn about or understand more fully that some of the people with diabetes in your community might be able to tell you. Are you planning a communication campaign targeted to people with diabetes? Are you thinking about putting together a new brochure with information about nutrition? Are you puzzled by health statistics about a segment of your community that suggest low awareness about diabetes self-care or barriers to care that you need to know more about? Or, do you simply want to learn more about people with diabetes from diverse cultures in your community? These and many other questions are an excellent starting place for planning a focus group study. Even if you have some expertise in one or more of these areas and have combed literature sources for insights, there is no substitute for seeing the faces and then hearing the stories of people in your community.

***What Do You Want to  
Learn? Defining Your  
Purpose and Approach***

Start your study by writing down the main purpose. Depending on the nature of your community and programs, your purpose statements might be similar to these examples.

- ◆ **Purpose:** To learn about the knowledge, attitudes, beliefs, and perceptions of people with diabetes in the community (or a specific neighborhood) and their families as background for developing communication strategies that will encourage and support more effective self-care.

A clear purpose statement serves as a foundation for quality research that will enable you to return accurate and useful information to the community to help prevent and manage diabetes.

- ◆ **Purpose:** To develop a clearer understanding of how families and the social circles of particular groups of people with diabetes influence self-care and then formulate strategies for facilitating family and social support.
- ◆ **Purpose:** To evaluate the quality of diabetes education efforts and materials provided by public health clinics in the community to people with diabetes in order to strengthen services.

Now you can begin planning how to go about conducting the study. Define the following:

- ◆ **WHO should be on your research team.** Do you already work with community organizations involved with the population you're interested in? Could you form new partnerships for your study? Do you already have—or need to hire and/or train—appropriate people to recruit participants? Moderate the focus groups? Translate the materials and findings?
- ◆ **WHO you need to hear from.** Do your groups need to include older people with diabetes? People whose primary language is Spanish? People with renal complications? Another segment (or segments) of the population? If you're planning a program or campaign, this decision is an important part of segmenting your audience into groups for which you can develop specially tailored messages or strategies.
- ◆ **WHERE and WHEN to hold the groups.** What is likely to be most convenient and comfortable for participants? Will the facility need to be large enough to accommodate observers? Will it have recording equipment?
- ◆ **HOW to recruit people.** Do you already have names and telephone numbers? Will it be possible to reach people by telephone? Will you need to provide information to people in advance of a phone call through flyers, church bulletins, or other means? What incentives will be important to encourage participation (e.g., transportation, babysitting, honoraria for time)?
- ◆ **WHAT to ask participants.** You have a general idea of what you want to learn, but how should the moderator proceed? What specific questions will encourage participants to share the information you want to know?
- ◆ **HOW the findings will be summarized.** What type of summaries and reporting will be important for your study? Who will review the results? With whom will you share the findings?

You probably won't be able to answer all of these questions initially. Don't worry! The answers to some questions, such as exactly how you will go about recruiting participants, will come later. Assemble what you can; you'll find that the gaps will be filled in as you go along.

#### *Put It in Writing*

**When you conduct your groups in a rigorous manner, your research methods help set high community standards for conducting research about public health issues.**

Try to put all the planning details for your focus group research in writing. Most of us are accustomed to writing out plans and budgets for projects—or at least planning to!—so this suggestion may seem obvious. But in case you're tempted *not* to prepare a fairly formal plan, there are some especially good reasons for recording the details for focus groups in writing.

**Reason 1:** A written research plan, even an evolving one, is a valuable tool for helping people focus on the purpose and methods determined to be appropriate. This is especially important for research that calls for the involvement of people other than you and your staff. Such people might include

- ◆ Moderators, recruiters, translators, and partner organizations.
- ◆ Gatekeepers—people whose support of your study can facilitate or preclude access to and cooperation from people you want to talk to. Gatekeepers can help or hinder your efforts to get permission to use convenient facilities or get in-kind donations of facilities or services that can enhance the research.

**Reason 2:** The better the record of how you go about your research, the better able you will be to build on what went well and modify anything that could be improved if you do more research in the future.

**Reason 3:** The more you have in writing, the more you will be able to share with others to help strengthen the quality and productivity of *their* focus group research. Collaborating on effective research methods helps to assure that people in other communities will not have to learn the hard way the lessons your research could teach them. The benefit: everyone accomplishes more on behalf of people with diabetes.

#### *Who Should Help?*

#### *Developing Partnerships*

**By developing partnerships for conducting the focus groups, you open a door that allows for a giving and receiving relationship that may benefit the community in other ways in the future.**

Never underestimate the extent to which your research will benefit from collaboration with a variety of people, particularly if the study will involve people of cultures, races, backgrounds, or circumstances unlike your own. In fact, it's simply wrong to attempt to conduct studies without seeking input from people who have expertise or organizational affiliations in the community. Bringing partners on board to assist in your research effort helps ensure that the needs and feelings of the focus group participants will be taken into account.

You may think of some partners automatically; others may be less obvious. You may wish to ask others who may have conducted research with your community of interest, for example, local university faculty, for their suggestions.

For potential partners, you may wish to look to

- ◆ Local clinic personnel.
- ◆ Leaders of local community groups, advocacy groups, and religious organizations.
- ◆ Local health department workers.
- ◆ Opinion leaders.

You may have several experts and partners working with you on a project. Not surprisingly, they may not all agree on the best way to carry out all project activities. For example, one person may believe that men and women should not be convened in the same focus group. Another may argue that a mixed group would result in more insightful discussion. Still another may point out that while separate groups are ideal, recruiting enough men (or women) who meet the screening criteria may prove too difficult a task. If you listen carefully to everyone's advice and rationale, you will be able to make informed decisions.

**Providing training for novice moderators will give communities valuable resource people if they seek more research in the future.**

Our groundwork with American Indian contacts alerted us to the prevalent feeling among this ethnic group that although they are regularly scrutinized and studied, they rarely see results or benefits from such research. This knowledge helped us to be more sensitive and to seek ways to ensure that the American Indian communities would benefit from their participation in our study. For example, we provided professional training for four American Indians on how to conduct focus groups. They then served as moderators for the focus groups on reservations. The benefits of training the four were twofold. First, because the moderators were from the same culture as participants, they could put participants at ease and understand the culturally driven group dynamics during the discussion. Second, the people we trained are now equipped with the skill and experience needed to conduct research themselves.

#### ***Who Else Should Be on the Team? Choosing Moderators and Translators***

A skilled moderator is key to your learning what you need from your participants. If you need the services of a translator, choosing a highly skilled translator can help you clearly understand your participants and also save time and money once you reach the report-preparation phase.

#### **Moderators**

Moderating a focus group requires skill. Don't be tempted to think that anyone can lead a group of people through a discussion. You don't want someone to merely get through a predetermined set of



#### **WE LEARNED . . . How critical to success partners can be**

A local research partner was the key to obtaining approval from tribal councils to conduct focus groups of American Indians on reservations. We doubt that we would have obtained approval without a partner contact to shepherd our request. Most of our partners were Indian Health Services staff members, but other partners—for example, a nurse whose health facility served primarily American Indians—also helped us.

Our request included an explanation of the purpose of our study and how the study findings would be used (in particular, some of the ways the study would benefit the population that participated), a copy of the moderator's guide, information about the qualifications of the research team members, and endorsements and letters of support from references.

Note: The approval process we followed is a prerequisite for research with most tribes. Because some tribal councils convene only once a month, allow two to three months in your research plan, if possible, for the process.

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broad questions; you want someone who can be counted on to *facilitate* discussion that is productive from a research standpoint as well as interesting and worthwhile for participants.

A skilled moderator can

- ◆ Quickly establish rapport with participants and put them at ease, especially those who may be nervous about what topics will be raised in the group discussion.
- ◆ Maintain an objective and accepting manner that encourages expression of different, even conflicting, opinions. A skilled moderator responds to participants' comments with statements—and body language—that say, “I think I understand what you are saying,” not “Yes, that is exactly right” or “No, I don’t agree.”
- ◆ Create an atmosphere in which participants can openly discuss a potentially sensitive health topic.
- ◆ Encourage everyone to participate, drawing out participants who are more reticent and deftly “controlling” those who try to dominate the discussion.
- ◆ Keep track of time, covering all of the topics in the discussion guide while also probing interesting statements and revelations.
- ◆ Remember what participants say and return to comments if they are relevant later in the discussion.
- ◆ Understand the cultural background and other characteristics of participants, especially issues that may influence group dynamics. This understanding includes the ability to comfortably speak the language participants want to speak.

How do you go about choosing appropriate moderators? First, investigate whether it will be possible to contract with a professional moderator—or moderators, if you anticipate that your study will encompass diverse groups. Although the services of a professional can be expensive, you’ll find that they’re often well worth the cost.

### 3. Conducting Effective Focus Groups

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Look for a moderator who has

- ◆ *Experience with health-related focus groups, ideally diabetes.* Bear in mind that it is more common for moderators to have experience with consumer product research than health behavior research. Also, many moderators will have little experience working with people with diabetes, people who have low incomes, or people whose primary language is not English.
- ◆ *A background similar to that of participants.* If possible, it is a good idea for the moderator to be of the same gender, age group, and race or cultural background as participants, especially if those characteristics are relevant to the research topic.

Must you adhere strictly to these guidelines? No. For example, many professional moderators, especially those with health experience, conduct successful groups on sensitive topics with people of the opposite gender and of a different cultural background than theirs. The only characteristic on which you cannot compromise is language skill. The moderator must be able to understand and conduct the discussion in the participants' primary language.

If you can't find, or afford to hire, professional moderators, it is possible to select and train people with the appropriate characteristics. What is essential is that the training be provided by an experienced professional moderator. This skill cannot be addressed fully in a single, hour-long session. Allow at least two full days for training.

When considering people to train as moderators, look for people who

- ◆ Have some familiarity with the focus group topic.
- ◆ Talk easily and comfortably with others.
- ◆ Listen responsively.
- ◆ Are pleasant and good-natured.
- ◆ Are composed and self-assured without being arrogant or conceited.
- ◆ Think quickly on their feet and will be able to probe issues not addressed directly in the discussion guide.

Formal training courses are also available—usually through market research firms. This option may be a worthwhile investment if you plan to conduct focus group research regularly. Having a trained

moderator on staff may justify an investment in formal training.

It's best to avoid sending inexperienced moderators into an actual focus group totally "cold." If possible, convene a short (one- to two-hour) mock focus group to give each newly trained moderator a chance to rehearse his or her new skills and get comfortable with the role.

#### **Translators**

If your groups are likely to be conducted in a language in which you are not fluent, you will need to include translation services in your plans. Ideally, the focus groups can be held in a location where a separate room will be available for observers. Then you can set up a closed-circuit television or audio playback equipment and monitor the session while the translator provides you with a sense of the discussion. (We cover issues relevant to facilities, observers, and recording later in this handbook.)



#### **WE LEARNED . . . How to train culturally appropriate people to moderate focus groups**

We had the resources to use 10 moderators for the diverse ethnic and racial groups in our eight-state study. Most of the moderators we used were professional, experienced people. The moderators for the American Indian groups, by contrast, were people we selected and trained specially for this study. The curriculum, taught by professional moderators, addressed general diabetes background information, health communication and evaluation research methods, and moderating focus groups. Curriculum segments included the following.

##### **Diabetes Background**

- Diabetes initiatives at CDC
- Available resources for diabetes education and prevention

##### **Health Communication and Evaluation Research Methods**

- Health communication and marketing at CDC
- Formative evaluation for diabetes programs designed for minority populations
- Survey research as an evaluation tool
- Case studies as an evaluation tool

##### **Moderating Focus Groups**

- Overview of focus group research
  - Mock focus group session (with moderator trainees as participants)
  - Moderator's guide and moderating techniques
  - Results of focus groups conducted to date with African Americans, Asian Americans, and Hispanics/Latinos
-

If a separate room won't be available, consider having the translator attend the discussion groups and then listen to the recordings of the discussion afterwards and either take notes for you or transcribe the tapes into English. This service, combined with the report you will probably ask the moderator to prepare, will give you a more comprehensive view of the discussion than you will obtain from the moderator's report alone.

Bear in mind that translators (and translated transcripts) are quite expensive. Fully explore the options that your research partners and moderators may be able to suggest before turning to commercial services—usually listed in the Yellow Pages of metropolitan area phone books under “translation services.”

***Who Is Your Audience?  
Defining the Composition  
and Number of Groups for  
Your Study***

Once you have assembled a team, take a closer look at the purpose statement and your early ideas about who to include in your groups. Now you should begin getting more specific about the composition and number of groups for your study.

#### **Composition of Groups**

In considering the types of people to involve in a focus group, a general rule of thumb is to put people together who will be comfortable with one another. If everyone has some obvious common ground, participants are more likely to be comfortable and open. For example, participants might be women under age 50 with a high school diploma whose diabetes was diagnosed within the previous two years. In addition to using demographic characteristics, some studies also consider other similarities (e.g., people who have indicated that they don't monitor their glucose as often as they should but are ready to start trying).

Be careful about mixing people from very different backgrounds. For example,

- ◆ People whose educational backgrounds and socioeconomic circumstances are very different—say, some have graduate degrees while others have only a grade school education—might not be comfortable together.

- ◆ People might defer to participants who are considerably older or who have positions of respect or authority.
- ◆ Men and women might not be comfortable discussing some personal topics in a mixed group.
- ◆ People who know each other might be less open about personal topics than they would be with strangers, or they might be reluctant to disagree with each other's opinions.
- ◆ Even among a major ethnic or racial group, people from different countries may not mix well or speak the same language. We wanted to represent American Indians, Asians, and Hispanics/Latinos in our study. But think about it; more than 500 American Indian tribes and Asian populations include people from several countries who speak many different languages. Similarly, many Hispanic/Latino cultures are represented in the United States.



#### WE LEARNED . . . How to make mixed groups work

We knew we wanted participants

- With non-insulin-dependent (type 2) diabetes mellitus
- Aged 40 to 70
- From diverse racial and ethnic backgrounds, with some representation of American Indian, Hispanic/Latino, Asian, and African American cultures
- From rural and urban areas in several states in different regions of the United States.

That's a lot of groups, without even addressing the guidelines we just spelled out about who to mix and not to mix. What did we do?

**Sometimes, we included men and women in the same group.** We conducted some groups with only men, some with only women, and some with both men and women. This gave us a good mix of different compositions and numerous opportunities to determine the effect of the mix or separation on the results. A case in point: Although many men with diabetes experience impotence, this issue came up in the men-only groups but not in the mixed-gender groups—quite likely because of the sensitivity of the subject.

**Sometimes, we mixed American Indians of different ages.** We had learned from several sources—the moderators, other American Indian advisers for our study, and the literature—that younger American Indians were likely to defer to elders, speaking very little in their presence and generally yielding the floor. Despite the fact that the mixed group was not ideal, all participants shared their stories, thanks to guidance from the moderator.

**Sometimes, groups included people who knew each other.** We found that having participants who know each other in the same group is sometimes unavoidable. On American Indian reservations and in remote rural areas, participants are likely to be acquainted. We tried not to include family members in the same group, but even that proved difficult. The moderator's skill in putting all participants at ease was essential to ensuring that participants discussed their views and experiences freely and openly.

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If it is not possible to separate people as we just recommended, a skilled moderator will be prepared to overcome some of the potential drawbacks to a particular mix. For example, the moderator may ask people to write down views that they may not want to voice (if it is clear that the participants are able to read and write, so this request does not embarrass anyone).

#### **Number of Groups**

It is generally very valuable to conduct at least two groups with each audience that you determine to be important (e.g., two groups of women, two groups of men, two groups of Spanish-speaking people). Such a setup provides you with an opportunity to compare the findings from the two groups. If you cannot afford at least two groups, it is entirely possible to gain valuable information from one. Keep in mind, however, that having several groups with each type of audience allows you to determine what comments were an aberration—attributable, perhaps, to the influence of an especially forceful participant or to two or more participants disliking one another.

When resources restrict the number of groups, you can increase your confidence in the results by sharing the findings more widely, perhaps with others who have conducted studies with similar purposes and participants. An experienced moderator who has worked with the audience the participants represent, the topics discussed, or both can also provide insight about the validity of your findings.

#### **Step 2: Determining Where and When to Schedule the Groups**

The most appropriate places to hold your groups are locations that will be comfortable and convenient for participants and suitable for food service, the use of recording equipment, and seating needed for research purposes. To increase the likelihood that participants will be able to and will want to attend, groups should be scheduled at times convenient for them.

#### ***Where Can You Hold Groups? Selecting Places***

Start by thinking about the location and features that will put your participants at ease:

- ◆ Where do your participants live?
- ◆ Do they travel by public transportation or by car?
- ◆ Are they likely to be healthy enough to climb stairs if there are no elevators to an upper floor?
- ◆ Will they feel secure attending a night session?
- ◆ Will they need a restroom very close to the discussion room?
- ◆ Will they need to bring with them children or other people (such as friends or relatives who drive them)?

Now think about the features that will be important for research purposes:

- ◆ Will you, observers, or a translator want to view the group?
- ◆ How much space will you need for serving refreshments?
- ◆ What type of recording are you planning? What space, acoustics, and electrical outlets will be needed?

Once you have an idea of the location and features that are important, you can begin to investigate. Two broad types of facilities are available: professional facilities at commercial market research firms and community sites.

First, determine whether there are any commercial market research firms in or near the communities where your participants live. (Bear in mind that some firms with facilities whose location is not appropriate for your study may still be able to identify suitable locations and conduct recruiting efforts for you.) Also, talk to your team and partners about suitable options in the community (e.g., community centers, schools, clinics, libraries). There are advantages and disadvantages to using each type of facility. If you use a local market research facility, for example, you will not need to be concerned about the quality of an audio recording of the focus group or where you will sit to view the group. And often, if the facility is located near your participants' neighborhoods, the firm may be able to provide recruiting services using your own lists of prospective participants or using names they already have in a database or can find by other means. If you use a community facility, you can save

money by doing some or all of the work yourself.

Let's look more closely at both approaches.

#### **Working with Commercial Market Research Firms**

Some communities—usually those in or near major metropolitan areas—have market research firms with facilities furnished and acoustically designed for focus groups: conference-style rooms equipped with audio- and videorecording equipment as well as adjacent rooms where observers can view and discuss a focus group in progress through a one-way window. These firms can also provide recruiting services. However, it is crucial to determine if their experience has included recruiting the types of people you want for your groups. Many market research firms, including some of the best-known firms in the country, *do not* have significant experience recruiting low-income participants or participants of varying races and ethnicities. The market research industry has been geared primarily to recruiting mainstream—usually middle-class to affluent—consumers for clients interested in evaluating products or marketing campaigns. However, with the growth of health-related research, as well as the more widespread recognition among consumer product companies of the importance of highly targeted marketing, there may be a firm near you that is appropriate for your study.

To see if a market research firm is located in or near the communities or neighborhoods where your prospective participants live, look in the Yellow Pages under “market research.” If you are planning to recruit participants in communities that are some distance away, a resource directory of market research companies, such as the *GreenBook*, may be useful. This helpful guide is published and updated annually by the New York Chapter of the American Marketing Association and is available both in print (for approximately \$100) and electronically. Market research firms are indexed in the guide by the types of services they offer, by geographic location, and by the names of principal contact people. See section 4 of this handbook for information about locating this and other resources.

If a traditional market research facility is appropriate, an advance reservation is needed to hold the facility. If the firm will also conduct recruiting for you, it will need time to provide that service, usually a minimum of two to three weeks prior to the date of a group. If your participants are likely to be difficult to find, reach, or persuade to attend, more time may be needed. (Many commercial market research firms are reluctant to book their facility unless they will also conduct the recruiting.)

Be prepared when you first contact a market research firm to discuss background information on your study and to describe the characteristics you want participants to have. This information will enable the firm to prepare an accurate cost estimate for providing or finding facilities (and related services such as refreshments and audio- and/or videorecording) and recruiting participants according to your criteria. Price quotations are usually prepared in about a day.

Facilities calculate their recruiting charges by estimating the time their recruiters will need to find, screen, invite, and persuade the designated number of appropriate participants to fill your groups. The easier it is likely to be for recruiters to fill your groups, the lower will be the cost.

In investigating a market research firm, be especially careful to ask questions about the firm's experience recruiting the types of people you want for your groups. For example,

- ◆ Ask if the firm has specific experience recruiting participants who fit the profile you describe. How do they go about recruiting for special audiences? What strategies do they propose for recruiting your participants? Do these strategies sound resourceful? Do they ask you insightful questions about your study?
- ◆ Does the firm have recruiters who speak the language your participants are likely to speak? Is someone available to prepare language-appropriate letters of confirmation and directions to the facility and to take calls from non-English-speaking participants?
- ◆ Does the firm have experience arranging for transportation or child care or accommodating other people who accompany participants to a group? Are they willing and able to handle this potential need if your study requires it?
- ◆ Do they have any experience accommodating special diets or specific ethnic cuisine that may be important for your participants?

Be sure to ask each firm you investigate for references—and check them. If possible, try to visit any firms that are nearby with people from your partner organizations and the moderator(s). Use your instincts. Are the people you talk to friendly? Do they seem interested in your study? Do they seem confident that they can conduct the recruiting you need? Do they get back to you promptly after you contact them? Does the atmosphere seem right for your participants?

The best recruiting scenario is one in which

- ◆ You have a list of names and phone numbers of prospective participants.
- ◆ The qualifying criteria for participation are relatively easy for people to meet.
- ◆ The topic is likely to be of interest to people you want to recruit.
- ◆ Your organization is both known to people and well respected.
- ◆ The facility is conveniently located.
- ◆ The incentives for participating are compelling.

In this instance, recruiting will be less costly and time consuming. But most health studies are not this easy. Instead, it is common

- ◆ Not to have names or phone numbers for prospective participants, or for participants not to “fit” in the databases of names that market research firms generally maintain.
- ◆ To need people with special characteristics that make finding and recruiting them a challenge (e.g., a primary language other than English, lack of transportation, health conditions that make it difficult to travel outside the home, living circumstances that may mean they do not have a telephone, immigration status that makes them wary of telephone calls from people they do not know).
- ◆ For research sponsors not to be well known to participants or for the notion of market research to evoke suspicion.
- ◆ For appropriate participants to live in communities or neighborhoods that are far from commercial focus group facilities.
- ◆ For limited budgets to preclude offering prospective participants compelling incentives to attend.

Imagine the number of calls—and the cost—to even *find* a household with someone who has diabetes, is willing to answer a recruiter's questions, meets the screening criteria, and is also willing and able to attend a group. The bottom line is that to recruit groups of people with diabetes, you will likely find it necessary to explore alternatives to market research firms.

#### Finding Community Sites on Your Own

If there isn't a suitable market research firm nearby or your budget rules out that option, consider the following possibilities:

- ◆ Other sites may be less expensive—or even free. You or your partners may be able to secure a site at no cost or at a special discount.
- ◆ Other sites may be more conveniently located for participants, thus facilitating recruiting and increasing the likelihood that people will show up. Consider this. Of the nearly 30 professional focus group facilities with an Atlanta, Georgia, address, only one that we know of is in the downtown area; and none is in a low-income neighborhood.

Visit potential sites to determine if they will be suitable for your groups. Try to get a feel for the community's perceptions of the facility. Your participants are more likely to agree to participate and to attend groups if they are familiar with your site and have had positive experiences there. Don't assume that potential participants have good feelings about a facility or organization just because it is intended to serve them.



#### WE LEARNED . . . About great sites for focus groups

We convened focus groups in the following sites:

- Conference room in a tribe-owned lodge
- Community center
- Elementary school classroom
- School kitchen/dining area
- Church fellowship hall
- University psychology lab
- Community college classroom

In other studies, people have arranged to use free of charge:

- Fire halls
- Church rectories
- Health clinics and hospitals
- Delis (after business hours)
- Library meeting rooms
- Bank conference rooms
- Agricultural extension office meeting rooms

Based on what you've decided you'll need for the groups, make a checklist for a visit or telephone call with a contact person. For example, you may want to investigate answers to these questions:

- ◆ Is the site accessible by public transportation? Is there safe parking for participants who will drive? Is the parking free or low cost?
- ◆ Is the facility in general, as well as the room where the group would be held, accessible to people with disabilities?
- ◆ How many people can the room accommodate? Is there space for audio and/or video equipment?
- ◆ Is there an adjacent room where observers could hear or view the focus group via closed-circuit television or audio feed? Remember, if you will have a translator to explain to observers what is being said during the session, a second room will be *essential*. If you will not need a translator and two rooms aren't available, check whether there is sufficient space in the focus group room for a few observers in addition to participants.
- ◆ Are the rooms sufficiently free from potential distracting noise from outside traffic or activities elsewhere in the building? In our study, one group had to shout to be heard above the noise of an air conditioner. We've also been in a location where karaoke singing began in an adjacent room before the focus groups concluded!
- ◆ Are there outlets for recording equipment? Will you need to bring extension cords and duct tape to secure them adequately to avoid a tripping hazard?
- ◆ Are there kitchen facilities (or sufficient space) for you to serve refreshments comfortably? Will you be permitted to bring and serve your own refreshments, or will you have to use the facility's food service or catering? Will you need to bring coolers and ice to keep refreshments chilled? Will you need cleanup supplies, such as paper towels and trash bags?
- ◆ Is there a telephone at the facility, and can participants call the facility for travel directions? If your groups will be with non-English-speaking participants, will there be personnel who can answer questions in their language?
- ◆ Is there space to accommodate babysitting if needed? Will the facility's liability insurance permit you to provide this service during your focus groups?

**Support the local economy of the community you're working with as much as possible. For example, during our study we stayed at accommodations on the American Indian reservations, ate in local restaurants, and hired local people when possible for food service and audio- and videotaping services.**

Don't expect the site to be perfect. Even commercial facilities have drawbacks. Your assessment should be designed to separate truly unsuitable locations from those that can be made workable with a little advance planning. For example, if there are no kitchen facilities, you can bring coolers and plan a menu that lends itself to easy transport and cleanup. This worked very effectively at more than one site in the Diabetes Prevention Marketing Study.

#### ***What Times Are Good for Groups? Setting a Schedule***

You will want to consider several aspects of timing in setting up your focus group schedule: the length of the session, the time of day, the day of the week, and even the season that is most convenient for the participants you will recruit. Focus group sessions typically last two hours. The most common times for consumer focus groups are Monday through Thursday evenings at either 6:00 p.m. or 8:00 p.m. If you plan to convene two groups on the same evening, schedule at least a half hour between the departure of the first group and the arrival of the second. This gives the moderator a much-needed rest and enables both the moderator and observers to modify the discussion guide, if appropriate. In addition, this assures that the room can be cleaned and set up for the next group of participants.

Some special considerations may dictate that you deviate from the scheduling just discussed. For example,

- ◆ If participants will be driving to the focus group or using public transportation, give some thought to the potential for traffic delays during rush hour in urban areas.
- ◆ Consider participants' safety. Will they feel comfortable going home after dark?
- ◆ Shift workers may be available only during very early or very late hours or on weekends. Similarly, people who work more than one job may be available only on weekends, if at all. Farm workers may be available only in the off-season.
- ◆ Some people (e.g., senior citizens with health problems or impaired mobility) may not have the stamina for a two-hour session.
- ◆ There may be special opportunities for recruiting a group before or after a class, church event, or other gathering that would make an unusual time an ideal time.

#### **Step 3:** **Recruiting Focus** **Group Participants**

Some focus groups can be put together quickly, in a couple of weeks; if you have more elaborate criteria for participant selection, it may take longer. Consider how much time you'll need before you set a date. Successful focus group recruiting involves

- ◆ Finding people who may be qualified.
- ◆ Determining if they are qualified.
- ◆ Persuading them to agree to attend.
- ◆ Making it convenient and compelling for participants to show up.

Whether you and your team will do the recruiting or a market research firm will do it, there are important issues relevant to each of these activities.

#### ***Where Is Everyone?*** ***Finding People Who May*** ***Be Qualified***

Think about where the people you want to recruit live or work. The most common way of contacting people for focus groups is to call them on the telephone, tell them about the study, ask a few screening questions to determine if they qualify, and, if they do, invite them to participate. Most market research firms maintain extensive databases of local residents' names, telephone numbers, and basic demographic profiles.



#### **WE LEARNED . . . About important scheduling issues**

In one study, women arriving for an 8:00 p.m. group observed that an all-male group was concluding. The women told the moderator that they would have felt more comfortable in the earlier time slot, so that they could have been en route home before dark.

In another study, groups of Hispanic/Latino migrant farm workers were convened after sundown in the summer—later than typical focus groups—to accommodate the workers' work schedule. The second group each evening was concluded earlier than usual to accommodate the workers' very early morning schedules.

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But recruiting by telephone may not be appropriate if

- ◆ You won't be using a commercial firm for recruiting.
- ◆ Your prospective participants aren't likely to have telephones, or you can't get the numbers. (Note, however, that many telephone databases are now accessible on the Internet at no cost. Several have home phone numbers for individuals all over the country, even people whose phone numbers are listed in someone else's name.)
- ◆ Your budget precludes calling households in your target area at random.
- ◆ Your prospective participants are likely to distrust someone they don't know who calls them about participating in a focus group (which many people may never have heard of).

In such cases, think about other ways you and your team could reach people. In our study, we found that we wouldn't have been able to recruit enough participants for several of our groups without using some of the following strategies:

- ◆ Alert and involve your partners! No doubt, many of them—or colleagues or other people they know—have contact with prospective participants. Clinic personnel, ministers, tribal and community leaders, and many others could inform people about the study and encourage them to participate.
- ◆ If you have addresses, you could mail letters to tell people about the study and invite them to call to see if they qualify. Consider who would be most appropriate to sign the letter, and choose individuals or organizations most likely to be familiar to and trusted by prospective participants.
- ◆ Post a notice in parks, senior centers, pharmacies, community newsletters or newspapers, church bulletins—wherever prospective participants might see it. Again, provide information about the study and encourage people to sign up on the poster (including providing their phone number), to call a phone number, or to speak with someone identified in the notice. Notices should outline the incentive for participating; characteristics people need to have to participate; the date, time, and location of the session; and the sponsor. Of course, you should identify the topic in broad terms (e.g., “your thoughts and opinions about health topics”).

### 3. Conducting Effective Focus Groups

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- ◆ Local radio stations or programs that serve your audience may be willing to mention your study and provide contact information.

In writing a notice, take care to keep the reading level low enough so the notice will be understood easily by the people you hope to recruit. If you are recruiting people who are less familiar with English than another language, develop information in the appropriate language. And if participants are asked to telephone recruiters, the call should be free.

Another way to find participants is to hand out flyers at grocery stores, banks, sports events, and shopping malls. If you think this approach might work for your study, be sure to secure appropriate permission.

#### ***How Do You Recruit Them? Assuring the Right People Are Invited***

You will want to develop a tool that explains the study to prospective participants, determines whether they fit the criteria you have defined, and persuades them to attend. Traditionally, this tool is a brief questionnaire, often called a “screener” because it is used to screen prospective participants to determine their eligibility. The screener can be read to prospective participants over the telephone or in person.



#### **WE LEARNED . . . How to recruit participants for focus groups**

Clinic personnel in several locations invited their clients to sign up to receive invitational phone calls. More detailed screening took place during those calls, and official invitations were issued as well.

For some groups, a nurse in a Harlem clinic invited clients to attend. She met the participants at a familiar spot and helped to ensure that they boarded the van that had been hired to take them to the focus group facility.

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A sample screener appears on page 3-24. As you can see below, the screener has four parts.

**Background Information About Participants.** Standard identifying information that you will need to keep track of including who has been contacted, screened, and recruited is placed here. It is a good idea to put this information at the top of the first page of the screener so it is easy to refer to—even if it is information you may not obtain until the end of the recruiting conversation.

**Explanation of Study.** Included here is information a potential participant is likely to need or want to know before answering your screening questions. Here, you would explain at least the basics of your study, such as who is sponsoring it and why. You will want to be sure to mention what language the group will be in. You will certainly mention that participants will be paid to attend a two-hour discussion group.

**Screening Questions.** Included here are questions that determine the eligibility of the prospective participant. Depending on the characteristics you want participants to have, you may include questions about health status, demographics, habits, or other topics. Interviewers ask these questions in an open-ended fashion, but a set of potential answers usually appears on the screener. Next to each question, instructions are written (in brackets) to prompt the interviewer. For example, your criteria may call for people aged 18 to 40, as the sample does; if the prospect says he is 35, the recruiter would say something gracious, such as, “Thank you, we have already completed our quota for your age group. May we keep your



#### **WE LEARNED . . . About the need to inform prospective participants of the language focus groups would use**

We offered some groups only in a language other than English, such as Vietnamese, Korean, Chinese, Tagalog, or Spanish. Instead of assuming that persons of each ethnicity were fluent in the language of their country of origin, recruiters made it clear that groups would be conducted in-language, so that people who were not fluent could opt not to participate.

Although participants in the study were not given a choice between English and another language, you could consider offering that choice. For example, if you were convening Latino groups, you could offer some in Spanish and some in English. During recruiting, you could ask participants to which group they would like to be assigned.

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### SAMPLE SCREENER

#### I. Background Information About Participant

Name of participant: \_\_\_\_\_

Address: \_\_\_\_\_

Phone or other contact information: \_\_\_\_\_

\_\_\_\_\_ Male \_\_\_\_\_ Female Recruited for: [Date/Time] \_\_\_\_\_

#### II. Explanation of Study

Hello, my name is \_\_\_\_\_. I'm calling from \_\_\_\_\_. We're helping the U.S. Public Health Service with a study about Americans' health. If you qualify for this study, you would be asked to come to \_\_\_\_\_ to give your opinions in a group discussion that would last about two hours. You will be paid for your time.

May I ask you a few questions?

#### III. Screening Questions

**Which of the following age ranges do you fall into?**

\_\_\_\_\_ 17 or younger *[Thank respondent and end call.]*

\_\_\_\_\_ 18 to 30

\_\_\_\_\_ 31 to 40

\_\_\_\_\_ 41 or older *[Thank respondent and end call.]*

**What is the last grade or year of school that you completed?**

\_\_\_\_\_ Grade school (or less)

\_\_\_\_\_ High school or equivalency

\_\_\_\_\_ Some college *[Thank respondent and end call.]*

\_\_\_\_\_ College graduate or higher *[Thank respondent and end call.]*

**Do you typically watch television news at least once a day?**

**[Note to recruiter: If asked, morning programs such as *Today* and *Good Morning America* count.]**

\_\_\_\_\_ Yes

\_\_\_\_\_ No *[Thank respondent and end call.]*

#### IV. Invitation

As I mentioned earlier, we are scheduling a small group discussion for the U.S. Public Health Service. If you are able to attend, you will be paid \$40 for your time, and refreshments will be served before the discussion. Will you be able to attend on [day/date] from [ \_\_ o'clock to \_\_ o'clock]?

**[Note to recruiter: Groups for 18- to 30-year-olds will be held Monday. Groups for 31- to 40-year-olds will be held Tuesday.]**

name on file?” This is an important point, because some people may be disappointed that they will not have a chance to receive the incentive they were told about.

Although writing a screener may seem straight forward, some concepts may be difficult to describe in short question form. You may want to ask potential participants whether they have had a diabetic retinopathy exam within the past year. In that case, it would be a good idea to explain that the diabetic retinopathy test is one in which the pupils are dilated, not the simpler vision exam they may have had for a new eyeglass prescription.

It can also be difficult to word questions clearly and in a logical sequence. Perhaps you want to recruit participants with diabetes who adhere to a strict diet, have eye and podiatric exams regularly, live with extended families including children under age 5, and are the primary food purchaser and preparer. In addition, you may want to learn their age and race/ethnicity. These criteria will require a fairly complex screener. The longer the screener is, the more important it will be to read it out loud before it is finalized. See if it “sounds” right and flows logically when you read the questions to yourself and others.

The English version of the screener used in the Diabetes Prevention Marketing Study is included in this handbook as Appendix B. (Bear in mind that not all participants in our study were recruited using this formal screener.)

**Invitation.** If the person meets the criteria, then he or she will be invited—and encouraged—to attend. If appropriate, reference to other services, such as transportation to and from the group or babysitting, is made. The recruiter closes with, “Will you be able to come?” If the person says yes, a request is made for his or her name and contact information.

You may find it necessary to relax some of your screening criteria if recruiting proves too difficult. For example, in one study on nutrition, potential participants were not invited if they or someone

else in their home was a vegetarian; had diabetes, high blood pressure, or high cholesterol; or ate a special diet of any sort. As recruiters made call after call, very few people were qualifying. As a result, the dietary criteria requirements were modified.

A word on *overrecruiting* is also appropriate here. It is common to overrecruit in case some participants forget to come, are not feeling well, or simply get stuck in traffic. We noted earlier in this handbook that focus groups typically have eight to 10 participants; if a group has more than 10 people, it is difficult to get everyone to participate actively. There is therefore a risk in overrecruiting. You may have *too many* people. But that's better than a group that is too small! In the discussion of logistics (step 5), we explain what to do if you have too many participants.

Do you have to conduct such formal recruiting? No. You might simply supply your community contacts with a list of criteria and allow them to decide who should be invited to participate based on their knowledge of the research purpose and the people in their community. Or, the recruiters might address a group of likely candidates—such as mothers attending U.S. Department of Agriculture (USDA) Women, Infants, and Children (WIC) educational sessions to receive their food coupons—and then ask them to call in to answer a brief list of questions.

#### *Will They Come? Persuading People to Show Up*

There are two things you can do to assure that the people you have invited will show up for the group.

**Make attending the group as easy as possible.** If the recruiting interviewer did his or her job well, participants have a good feeling about the focus group and are looking forward to attending. Right after the interview, send each person a confirmation letter with clear directions to the focus group location, including instructions about public transportation or travel arrangements you may decide to make (e.g., you may want to arrange rides for participants). If you will offer babysitting, mention that in the letter as well. Include a contact and phone number for people to call if they have questions or problems.

Emphasize that because the focus group is very small, their participation is important and that you are counting on them. If some or all of the participants do not speak English, make sure they receive information in the language they need and that someone who speaks that language is available to answer questions if they call. And be sure to call all participants a day or two before the session to remind them about the group and see if they have any questions.

Transportation and child care are common barriers to attending focus groups for lower socioeconomic status populations. Both can be expensive and difficult to access in some locales. If you or your research partners determine that these concerns will hinder recruitment, consider some ways to help potential participants. For example, you could offer bus tokens or paid taxi cab rides, pick up participants at their homes or at a designated meeting place using your own cars, or borrow a bus or van and driver from a clinic, school, or reservation.

Providing child care, while often invaluable, presents several challenges. First, some facilities may balk or refuse to allow babysitting on their premises for liability reasons. Your research group should also consider your own liability in the event of an accident. Second, children must be in a room nearby enough for the parents' comfort yet sufficiently separate from the focus group room to prevent distractions. In one instance during the Diabetes Prevention Marketing Study, a group was interrupted by a babysitter whose young charge was crying for her mother. The little girl spent the remainder of the session sitting on her mother's lap and the discussion went smoothly, but the research team was lucky that the child's presence was not disruptive.

**Give a monetary incentive when possible, particularly for low-income groups. Some participants with low household incomes may need the money to buy essentials. One woman told us that the incentive enabled her to pay her overdue electric bill.**

**Provide incentives for attending, and note them in the confirmation and reminder activities.** It is customary to pay focus group participants. Commercial focus groups with consumer participants typically pay each person \$40 to \$50 and provide a meal appropriate to the time of day. But some budgets preclude an incentive, and some agencies forbid one! When making decisions about the type of incentive to provide, bear in mind that a *monetary* incentive can be particularly effective. (Note: It is wise to pay participants, especially those who may have low incomes or may be undocu-

mented immigrants, in cash. Some may not have a bank account and might have to use a check cashing service and pay a fee for the transaction.)

Other, less expensive incentives include donated gift certificates, bus tokens, and gift bags. Be creative. For example, a local clinic may be willing to offer coupons for a free clinic visit (e.g., for blood glucose test) as an incentive. In some cases, receiving a meal may be sufficient incentive, especially if group members see their participation as helping to improve their community's health. Or, in smaller or more rural areas, consider making the groups part of a social event. Encourage participants to bring their spouses and children, but exclude them from the room where the discussion is held.

#### **Step 4: Developing the Discussion Guide**

A discussion guide is the tool that the moderator uses to facilitate a focus group. The guide is designed with the research purpose, the normal flow of conversation, and group dynamics in mind. It should be prepared well in advance of a scheduled group so that there is time to circulate it among partners and other interested people for comments. You want qualified reviews from people who can assess both the questions in the guide and how culture, language, and other important factors will be taken into account.

If you have hired one or more professional moderators, capitalize on their expertise to help you develop an effective guide. The best approach is for you to develop a set of questions that you want answered. Then allow the moderator(s) to recommend ways to get those questions answered by participants in a group setting, including suggesting the wording and the order of the questions.

If your study will include groups conducted in languages other than English, it is a good idea to assign the task of translating and adapting the guide to the moderator (or moderators) who will conduct those groups. This will enable the moderator to recommend modifications to make the guide work well with participants from particular cultures. In other words, the guide should be *culturally adapted*, not translated. A verbatim translation of an English guide is seldom, if ever, likely to work optimally with non-native English speakers.

#### *How Do You Ask the Right Questions? Components of a Guide*

Discussion guides typically have four components: (1) an opening and warm-up, (2) a set of discussion questions, (3) a “false” close, and (4) a summary and dissemination of information.

**Opening and Warm-Up.** In the opening moments of the focus group, the moderator must put participants at ease and establish a rapport with and among them. Don’t be tempted to try to save time by moving quickly to the “real questions.” The time invested in putting people at ease is time well spent. It is crucial to get the most out of the discussion that will follow. The moderator will also use this time and the interaction that is occurring to assess who may need to be drawn out and who may have to be restrained from dominating the later discussion.

The beginning of the guide should outline the general wording the moderator will use to

- ◆ Welcome participants and introduce himself or herself.
- ◆ Explain the general purpose of the discussion and why the participants were chosen.
- ◆ Explain the presence and purpose of recording equipment and introduce observers.
- ◆ Outline general ground rules, such as the importance of everyone speaking up, talking one at a time, and being prepared for the moderator to interrupt to assure that all the topics can be covered.
- ◆ Ask the group what language they want to speak (if participants were not asked during the recruiting process). This is a rare occasion in which the moderator will ask the group to reach *consensus*. Once the language is selected, it is the moderator’s job to ensure that participants speak only that language throughout the group discussion.
- ◆ Address the issue of confidentiality. Commonly mentioned safeguards include the fact that participants’ names will not be mentioned in the report and that tapes will be used only for research purposes.
- ◆ Invite the participants to introduce themselves. The purpose of these introductions is to give each participant a chance to hear himself or herself speak. Participants who have heard themselves speak at least once in the group are more likely to

participate fully.

As for the kinds of questions the moderator might ask, participants are usually asked to talk about things that demonstrate that they have something in common, such as where they were born or what types of physical activities they do on a typical day. If participants have all been newly diagnosed with diabetes, you might include a question about when they were diagnosed. Avoid questions that could reveal potentially sharp contrasts between people. For example, avoid asking what participants do for a living—unless relevant to the discussion topic—because occupational differences, or unemployment, can embarrass or set apart some participants in a way that impedes rapport.

To keep everyone who reviews the guide focused on the research purpose and to facilitate more creative and relevant feedback on the guide, put the statement of the purpose of the focus group at the top.

Think about cultural factors as you consider the wording of the opening statements and ground rules. For example, moderators often mention to the group in their opening statements that because there are so many important questions to discuss, they may have to interrupt participants to move to another topic. But while it is important for the moderator to manage time effectively, some cultures may view such interruptions as inappropriate.



#### **WE LEARNED. . . How the American Indian culture views interruptions**

It is customary for moderators to warn participants that interruptions may be needed to keep the discussion on schedule. In our study, the American Indian moderators explained that interrupting, even to change topics, is considered disrespectful, especially if a younger person interrupts an older person. As a result, this time management technique was used sparingly and delicately during the American Indian groups. For particularly time-constrained groups, moderators addressed the issue in their opening remarks in a culturally sensitive way. For example, one moderator said to a group of Shoshone women, “I might have to interrupt and ask you to shorten what you’re saying, but I don’t want that to hamper your ability to tell your story the way you’d like. If we weren’t in this forum but were at my home, I wouldn’t ask that of you. I would let you speak for days on end, and I’d listen respectfully. But under these conditions, I must step outside that cultural practice and ask you to understand if I need to interrupt.”

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If you have overrecruited and too many people show up, it is customary to invite everyone to enjoy refreshments. Then you can explain that the turnout was unexpected and the room is too small for the entire group. Some people may be very disappointed that you won't be listening to their opinions after all, especially after they set aside the time and perhaps even went to some trouble to attend. Have a *plan* for selecting who you will ask to stay and who will be excused, such as taking the first to arrive or taking as many men as possible for a mixed-gender group. Thank those whom you excuse and provide them with the incentive you promised.

If you have an experienced professional moderator, he or she may be able to handle a larger group, depending on the time available and the nature of the topics. If so, you can avoid the awkwardness of sending anyone away. Be aware also that it would be an insult to send away participants from some cultures.

**A focus group can be a remarkably positive experience for both the researchers and the participants. Researchers can explore their public health research goals, while participants can learn from one another and experience the positive feeling that people typically get when others validate what they say.**

**Discussion Questions.** The heart of the guide is this section, where the topical questions the moderator will ask are listed. It is a carefully crafted tool for fully engaging people in an interactive discussion. But nonetheless, it is a guide, not a script! If the conversation takes an unplanned but potentially fruitful turn, the moderator should have the authority to pursue new directions. The unexpected may reveal just what you needed—or at least indicate that questions on that topic may need to be added to the guide for future groups.

First, a word about ordering. It is rare for a moderator to ask the most important questions first. He or she may save some of the most crucial questions for later—when people are warmed up and comfortable enough with one another to be candid and expansive in their discussion. For this reason, it is a good idea to assign a specific length of time for discussion of each major topic in the guide. A good moderator will understand what is important overall and will use the time assignments as a gauge for when to move to a new topic. For example, perhaps you want the moderator to facilitate discussion on participants' feelings about a particular health problem, the influence of their families on their ability to cope with the problem, their experiences with medical care related to the problem, and their suggestions about ways to help others understand

the problem. First, set priorities; then assign less time to topics where brief discussion is likely to suffice and more time to topics that you view as crucial.

Be sure that your moderator also knows the relative importance of different sections and questions so that he or she can make good decisions if it becomes necessary to end the discussion a few minutes early. Your moderator should have the latitude to skip or only quickly address some portions of the guide if participants' energies are flagging seriously.

**A focus group gives people the opportunity to interact with others who share a similar problem. Many participants in our study said that they had never spoken with another person with diabetes about the illness.**

Some other tips about discussion questions are given below:

- ◆ *Use mostly open-ended questions because they tend to elicit more discussion more quickly than questions that can be answered with a single word.* For example, say, "What qualities would you say a good doctor or nurse should have?" rather than "Is compassion an important quality for a doctor or nurse to have?" Closed-ended questions can be useful for asking participants about portions of the guide. For example, ask, "Overall, would you say this brochure has about the right amount of information?"
- ◆ *Ask general, impersonal questions earlier in the session.* Save personal questions for later, when the group is more comfortable with the process. For example, ask, "How common do you think diabetes is in this community?" before you ask, "What role does your family play in your care?"
- ◆ *Use neutral questions rather than loaded questions.* For example, ask, "What are some reasons people have difficulty managing diabetes?" not, "Why don't you exercise and avoid fats when you know you should?"
- ◆ *Ask one question at a time.* For example, don't ask, "How does this message make you feel, and what suggestions do you have about it?" Discuss the first question fully, then move to the second.
- ◆ *Avoid putting participants on the defensive by refraining from asking "Why?"* Instead, try statements like, "Tell me about what makes you feel that way" or "Tell me more about your thoughts on that."
- ◆ *Plan time for questions, answers, and follow-up exploration of participants' answers.* How people respond to each other's answers provides information that is just as valuable as the original answers themselves.

If you want to obtain participants' views of materials—sample print materials or a video script, for example—the guide should include the general wording the moderator should use in introducing the material. Think carefully about what materials to use in a focus group setting and about any difficulties participants might have. For example, if you want to test print materials, alert potential partici-

pants to this plan during recruitment to allow someone who has extremely poor eyesight or literacy problems to decline gracefully. When introducing materials, a good moderator also will be alert to these possibilities and will take steps to minimize embarrassment.

For suggestions about the kinds of questions to ask your groups, see Appendix C. There, you'll find some ideas for questions that can help achieve different research purposes.

During the course of a set of focus groups, you may find the need to modify the guide. With many research methods, proper protocol dictates that the instrument remain exactly the same throughout the entire study. But the beauty of focus group research is that you can adapt the moderator's guide during the course of your research. For example, if you find that groups have difficulty answering an abstract question, rephrase it. If a particular question is not working at all, abandon it (provided it's not central to your research purpose) and dedicate the discussion time you gain to a more central question. Or, perhaps participants tend to name the negative aspects of a program, even though they have been asked to discuss the positive aspects first. Think about changing your guide to agree with the order participants apparently are more comfortable with. Finally, if an unexpected issue is raised by one group, you may want to ask future groups about it as well.



#### **WE LEARNED . . . To avoid abstract questions**

We wanted to know more about how participants thought about diabetes conceptually or metaphorically, so we included questions about those issues. But participants found it difficult to respond meaningfully to such an abstract notion on the spot. Try posing some of the potentially unproductive questions to colleagues or thinking about how you would answer them before including them in the guide.

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But that's not to say that all changes are acceptable. Give each group an opportunity to react to the same materials. For example, if you are testing campaign messages and two are clearly being better received than a third, don't abandon the third midway through your study. Knowing why a message doesn't work is often as valuable as knowing why another message does work. Also, ask all your groups about the same broad topics so you can accurately discern themes across groups. In short, consider whether the change to the guide will help you achieve the purpose set forth in your purpose statement. Also, consider whether you will still be able to compare groups and establish themes in participants' responses.

**“False” Close.** If observers will attend the group and can be accommodated in a room separate from the focus group, it is a good idea to build in a “false” close—time at the end of a group to get observers' views on any additional questions that should be posed to the group during the final minutes of the discussion. To fill that time, the moderator might give the group participants a task—a short questionnaire to fill out, for example, a second look at artwork, or a topic that needs further discussion. In some cases, the moderator indicates that he or she is going to step out of the room to check on the incentives. In other cases, the decision is made to simply tell participants that the moderator is checking whether observers have any additional questions. (Listen to participants' discussion during the moderator's absence. Often, it is quite revealing.)

Regardless of which approach is used, the check-in with observers must be brief. In addition, there will be very little time for additional questions. If there is a crowd of observers, consider writing down one or two key questions from the observer group and then



#### **WE LEARNED . . . About cultural sensitivity issues in the study**

During our study, several American Indian participants were hesitant to answer questions about traditional healing remedies, explaining that the information was sacred. We respected this cultural belief and did not probe further. In addition, prior to several American Indian groups, participants sought an opportunity for a brief group prayer. The research team, research partners, and the moderators for those groups had anticipated that request and were happy to participate.

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designating one person to meet the moderator in the hallway to pass on the questions.

**Summary and Information Dissemination.** When the moderator returns, he or she typically asks participants to summarize their thoughts about some of the most important aspects of the discussion. The moderator works into this discussion the observers' questions as well.

**Offering information at the end of the session is extremely important. Even people who have had diabetes for several years may have questions—and misconceptions. Some participants in our study stayed 45 minutes after the group had concluded to find out more about diabetes.**

The closing minutes of the focus group are also a time for you to provide information for participants—a toll-free phone number, printed information, and an expert to answer questions and correct any misconceptions about important health issues that were voiced during the discussion. Because the moderator is unlikely to be an expert in your field, an expert should join the group at the end, if possible. In correcting participants' statements, for example, that diabetes is caused by eating too much sugar, the expert should be careful not to offend participants or make them feel bad for voicing incorrect beliefs.

When the discussion with the expert is finished, the moderator thanks everyone and escorts or directs them to the area where the host provides each participant an envelope containing the incentive.

A copy of the English language version of the discussion guide from our study is included in Appendix D. There may be some questions and approaches in it that you could use in focus groups in your community. Note that this is the *full* guide. In the course of the Diabetes Prevention Marketing Study, we discussed the guide often and modified it for each set of groups to add or eliminate questions on the basis of what we had learned would work best or was needed to obtain better information.

## **Step 5: Logistical Details and Procedures**

Logistical issues can set the stage for a successful focus group. Participants and observers will be served refreshments. The focus group room will need to be set up. And note takers and observers—together with the moderator—will begin recording and considering the information that participants share.

#### ***What to Eat? Planning Refreshments***

Serving refreshments or a meal appropriate to the time of day is in keeping with creating a comfortable atmosphere for participants. Figure out when and where you will serve the food and beverages. In a commercial facility, food is ordered in advance and participants are served before the group discussion begins. Scheduling refreshments before the formal discussion can provide an important opportunity for participants to meet one another informally and to socialize. It also allows a cushion of time for latecomers. (If you will offer refreshments or a meal before the session, you'll want to allow sufficient time.) It is also appropriate to serve beverages during the group session. If you are using a community site and have a spacious kitchen and a pleasant room that is separate from the discussion room, you have more options. If only one room is available, participants should eat before or after the discussion. It is preferable not to serve food during the group because the noise of eating can obscure the conversation on tape.

Planning a menu involves several considerations:

- ◆ Your budget and the possibility of partners or others preparing or donating food or supplies.
- ◆ Participants' dietary preferences and needs based on health, culture, and religion.
- ◆ Presence of kitchen facilities or other space and equipment for serving and dining.
- ◆ How far you have to transport food.
- ◆ Restrictions on what you can serve or who you may hire to serve (e.g., liability issues, health department regulations, kosher facilities, contracts with unions or caterers).
- ◆ Time available.



#### **WE LEARNED . . . About making food selections carefully**

We provided culturally appropriate food whenever possible. For example, some American Indian research partners provided their traditional fry bread and other items. Also, researchers decided to provide healthier food choices such as sugar-free and low-fat as well as less-healthy choices, so participants would not feel they were being pressured to eat only the "right" foods.

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#### ***Are You Ready? Setting Up the Facility***

If you are using a commercial focus group facility, your research team will not need to do much setting up. If not, and if you are using a location such as a community center or school, be prepared to do all of the preparation work. You'll want to make sure that everything is completely ready before participants begin to arrive.

Here are some tips:

- ◆ Arrive early!
- ◆ Designate in advance a greeter or host to welcome participants.
- ◆ If needed, post signs to direct arriving participants to the right room or area.
- ◆ Have a sign-in list ready so participants can sign in as they arrive.
- ◆ Have the discussion room all set up: "tent cards" with participants' names, paper and pencils, and other materials (e.g., posters).
- ◆ Complete a sound and video check for all recording equipment.
- ◆ Make sure the refreshments are ready to serve.
- ◆ Know where the restrooms are so you can direct participants and observers.
- ◆ Have the incentives in individual envelopes and ready to distribute.

#### ***How Will You Remember Everything? Recording and Note Taking***

Focus groups yield substantial information, so it is important to carefully consider how you will capture as much as possible to discuss and interpret later. We have found using a mix of audio recording and video recording (or both) and observer notes to be quite effective.

#### **Recording Equipment**

Here are some tips on recording equipment:

- ◆ The facility where you will hold the groups may have some or all of the equipment you will need. A nearby school might provide recording equipment or services at a nominal cost.

- ◆ In metropolitan areas, there usually are equipment rental companies, whose staff can advise you on the most appropriate equipment.
- ◆ If you are able to hire professional moderators, many provide high-quality audio recording devices as part of their service. Regardless of who will provide recording devices, note that less expensive audio equipment picks up quite a lot of external noise.
- ◆ If observers will be in an adjacent room, include some type of closed-circuit system (or audio feed) so that they can both see and hear (or just hear) the focus group. Don't forget the special audio needs if a translator will be present. You'll want the translator to be able to hear the group, and you will want to record the English-language "simultaneous interpretation" he or she gives you.
- ◆ If you plan to show participants a videotape, you will need a television and VCR in the discussion room.
- ◆ Don't forget extras: extra video and audio tapes, extra batteries, extra extension cords, and extra tape to secure cords to the floor.

#### **Observers and Note Takers**

Plan carefully who will attend the focus groups as observers. To show respect for your participants, no one should attend your groups simply for entertainment or out of curiosity. It could be helpful for a research partner who is a trusted community member to meet and visit with participants at the group site. Keep in mind, however, that participants may speak less openly if they know that he or she is listening. For example, although a well-liked clinic nurse may put participants at ease upon arrival, they may not offer constructive criticism of the treatment the clinic provides if they believe that the nurse is listening.

If you plan for observers to meet participants, ensure that observers dress appropriately. Meeting men and women dressed in business suits who will watch them from behind a mirror probably would make most participants uncomfortable. At the opposite extreme, observers who are dressed too casually (e.g., in blue jeans) may send an unspoken message of disrespect.

Details such as the organizational affiliations of observers are not necessary to share unless participants ask about such issues. The

**Treating all participants with the utmost respect is important not only because it's the right thing to do, but also because persons of lower socioeconomic status, in particular, may have been shown little respect by society in other situations.**

moderator will usually explain that observers are present because they are very interested in hearing participants' thoughts and to help the moderator recall what was said. For groups in which some participants may be undocumented immigrants, there may be special concerns about observers. As noted earlier, moderators should bear in mind that those participants in particular may feel some anxiety about being observed and should respond accordingly. In general, treating the observers' presence as the standard and accepted practice that it is, can be more calming than being overly reassuring or detailed in the explanation.

Focus group observers are usually kept apart from participants, to the extent of even having a separate entrance at a facility. Some reasons for this separation include

- ◆ Reducing participants' feelings of being watched and increasing their openness.
- ◆ Eliminating potential disruptions from observers (e.g., distracting movements, coughing).

Although separating the observers is traditional, in our study we found, by contrast, that minimizing the separation of the observers was a positive step. If observers will remain in the discussion room they should be briefly introduced. The rule of thumb should be to do what will help your participants feel most comfortable. Your research partners may be able to offer some advice.



#### **WE LEARNED . . . About the signals that clothes can send**

Researchers in the Diabetes Prevention Marketing Study wore casual clothes to American Indian focus groups, as did the moderators for those groups. The moderators and research partners had explained that formal dress, such as jackets and ties, might not be well received by participants. Conversely, the moderator for a set of Hispanic/Latino groups wore a suit and tie to groups, explaining that participants would feel most comfortable with a group leader who was more formally dressed. Observers should consider dressing less formally, especially if they will be introducing themselves to groups that may include undocumented immigrants. Rely on your research partners to help answer these questions for your population and your specific geographic area.

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At least one person on the research team should be designated as the note taker for each group. Recording equipment can break down, and observers' notes may be the only comprehensive record of the discussion. If all observers take notes—or at least summarize their impressions following the group—it would be helpful to your analysis. Each person interested enough to attend has an important perspective to contribute.

Give note takers guidance for doing the best job in a focus group setting. Here are some helpful tips you may want to share with your note takers:

- ◆ Review the discussion guide in advance to become familiar with the purpose and key questions. Doing so will make it easier to judge what information is most important to capture, particularly if the conversation becomes fast and lively.
- ◆ If note takers are seated in the same room as participants, they may find it helpful to draw a small sketch of the room, with the table and participants' seat locations.
- ◆ When noting a question asked by the moderator, underline it or otherwise designate that the person speaking is not a participant.
- ◆ Be alert to participants' body language and mannerisms as well as their words. For example, if you are testing concepts for a nutrition campaign targeting diabetes control, note takers should record participants' facial expressions when the concepts are unveiled. Or, if one participant says, "My doctor did not give me enough information about diabetes when I was first diagnosed," and the rest of the group nods in agreement, note takers should record that fact.

## **Step 6:**

### **Interpreting the Results**

The diversity of participant responses and the sheer amount of information, especially if there are several groups in the study, makes analyzing focus group findings a challenge. In addition, the information is qualitative, not quantitative; you can't simply count how many times people said something to analyze your findings. And not just words are important. Hearty laughter and blank stares can represent important findings, even when no words were spoken.

#### *What Have You Learned?*

#### *Figuring It Out*

Following these steps will help you turn the information you have collected into a written document that you can use for reporting and program planning.

**Hold a Debriefing with Observers.** It is generally ideal for the team—researchers, the moderator, and observers—to convene immediately following the groups, when all impressions are fresh. A gathering early the next day is sometimes planned; waiting any longer than that is not recommended, because memories fade quickly. If held right after the group(s) this discussion should not be a heavy work session, because everyone will be tired from the hard work of listening closely to the groups. Rather, the debriefing session is a time to summarize and to share and compare impressions. It is also an opportunity to discuss modifications to the guide and procedures that might be important for subsequent groups.

Have at hand all the various records—the notes of observers and researchers and the tapes. It is a good idea for at least one person to take down the main points of the debriefing discussion. Or, you may decide to tape record this discussion, too.

During the debriefing, you might want to discuss

- ◆ Impressions of participants' answers to key questions.
- ◆ Impressions of participants' reactions to materials introduced during the group.
- ◆ Interpretations of participants' comments or behavior.
- ◆ Modifications to the guide (e.g., eliminating some questions, changing the wording or order of questions, adding new questions, changing the amount of time devoted to a particular topic).

**Arrange for Transcripts.** If your groups have been audiotaped, have the tapes transcribed to supplement the notes that observers have taken and provide a written record that can be read quickly. The transcripts also are a good source for verbatim quotes from participants to illustrate key points and conclusions in any reporting you do.

Obviously, the more complete and accurate a transcript is, the more useful it will be. To produce the best possible transcript

- ◆ Try to find a transcriber with experience transcribing focus group tapes. The number of people talking—and possibly poor acoustics in the focus group room—can make transcription a very challenging task.

- ◆ Provide the transcriber with clearly labeled tapes that display the topic, date, and time of the group.
- ◆ Brief the transcriber on the purpose of the research and provide a copy of the moderator's guide to familiarize her or him with the main discussion topics. You may also want to provide a copy of an observer's notes to help clarify something that is difficult to hear on the tape.
- ◆ Also provide the transcriber a list of key words and phrases and their meanings; the names of the participants in each group; notes about participants' vocal characteristics, to help the transcriber identify participants; and guidelines for the editorial style you want to use (e.g., preferred headers, whether page numbers are needed, whether a cover page should be included).

For groups that will be conducted in a language other than English, determine *before* the groups how you will handle the transcriptions. (Transcriptions that must also be translated into English are very expensive, especially those in languages other than Spanish.) If a translator provided a simultaneous translation on audiotape, the tape can be transcribed. Or, rather than producing a verbatim transcription, you can have someone who is fluent in the language listen to the tape of the group, take detailed notes, and then translate the notes into English.

#### **Prepare a Summary of the Key Findings from Each Group.**

The moderator is usually asked to prepare a brief summary (sometimes called a "topline" report) of the findings for each group, using the observer notes, debriefing notes, and transcripts. You may choose to do this yourself instead. You and your partners can use these summaries to make your overall research findings. These summaries usually include

- ◆ A profile of participants.
- ◆ The main themes that emerged for each key topic in the guide.
- ◆ Especially salient or striking quotes.
- ◆ The degree of consensus on key topics.

The last point is not easy to do. In assessing how widely a view is held, you must consider

- ◆ Whether people nodded in agreement or dissent—not just what was vocalized.
- ◆ Whether the group was polled on an issue.

As noted, counting responses doesn't "work" the way it does with survey data. In a focus group, people are apt to qualify or explain why or how they think or behave a certain way. It is probably those explanations that you're interested in collecting.

**Circulate the Summaries Among Key People and Ask for Feedback.** It may be useful to have a variety of people review the summaries, including observers, other research partners, and even additional experts who have not been involved in the research process to date. From the observers, you want to know if the summaries agree with their recollections. Is anything important missing? From all the key people, you want to know how the findings compare with what they expected. What did they learn from other studies? What remaining questions should be considered in future research?

**Prepare a Report on the Full Study.** With this feedback, you are prepared to tackle the job of synthesizing the individual findings into one master report. Your own experience along with others' feedback will alert you to important comparisons and contrasts to highlight. Note areas where findings that struck people as unusual mean that a careful check of the transcripts is needed. More generally, note the direction of any decisions that will likely be made based on the findings.

Whether you will conduct a more formal analysis to prepare the full report as well as the format and depth of the report depend on both resources—how much time and money you have to devote to the reporting—and what such a report should accomplish. Ask yourself the following questions:

◆ Why is the information needed?

Will it be used in public forums, only for the record, or for internal decisions? Will decisions be made based on this document? Will the document be copied in parts, published in whole, or likely not reproduced at all?

◆ Who is the target audience for the findings?

How well do they understand focus group methodology? What is their reading style? Do they prefer more detailed, narrative text or bullets? Will they be impressed by a lengthier report, or will they be unlikely to read a hefty document? Will there be public or media interest in the findings? Will the information be used for testimony to obtain grant money? To make decisions involving significant financial resources?

◆ What resources are available?

A report on the findings from a series of focus groups can range from a few hundred to many thousands of dollars. Don't plan a "Mercedes" analysis if you have only one person, one week, and \$1,000. If you need to present findings in a week, plan a brief summary incorporating the most important details about the groups and the findings rather than a 100-page report.

If you have the resources, you might want to explore some of the interesting analytical techniques that are sometimes used for large studies. For example, there is a wealth of information—even computer software packages—on analyzing focus groups using ethnographic principles developed for anthropology research. The "Toulmin method of argumentation" is another way to organize participants' views. Another technique is "grounded theory procedure." However, these techniques can be time-consuming and generally require consulting expertise that may be too costly for most studies. Check the materials we've listed in section 4 of this guide for an overview of some of these techniques.

◆ What logistical issues are involved in writing the report?

Where are the members of the research team located geographically? Will everyone work from the same computer network or at least use compatible software?

Depending on the answers for these questions, your report might have some or all of the following sections:

◆ Executive summary of the findings.

- ◆ Explanation of the background and purpose of the study.
- ◆ Overview of the methodology (how the focus groups were recruited and the screening criteria used, who participated and what the key topics were, and, if appropriate for the likely readers, background on focus group research in general).
- ◆ Findings, with a summary of the main themes, contrasts, and quotations.
- ◆ Implications or conclusions.
- ◆ Appendices, such as the screener, the moderator's guide, and copies of materials the participants reviewed.

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We look forward to hearing about the research you undertake and the lessons you learn. The more we share our understanding of what it is like to live with diabetes, the more we can do for the communities in which we work. In the following sections, you'll find resource information, followed by appendices with sample materials from the Diabetes Prevention Marketing Study. Good luck!



## Summary

- ◆ Develop a clear statement of purpose.
- ◆ Seek partnerships and assistance among respected and well-connected groups and individuals in the community in which you will conduct groups.
- ◆ Select a professional moderator who is a good match with your participants or train a member of the community.
- ◆ If you hire a translator, he or she should be skilled in simultaneous translation.
- ◆ To facilitate conversation and support your research goals, participants should share a set of selected characteristics.
- ◆ Either professional facilities or other sites may meet your needs.
- ◆ A variety of strategies are available for recruiting focus group participants.
- ◆ Your screener should prompt for background information on participants and include information about the study, screening

### *3. Conducting Effective Focus Groups*

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questions (in a logical order), and an invitation to participate.

- ◆ It is worth striving to provide attractive incentives for participants to attend. Also, by scheduling and locating groups conveniently, you can make participation an easy and enjoyable experience for community members.
- ◆ A discussion guide typically has four major components: (1) an opening and warm-up, (2) a set of discussion questions, (3) a “false” close to give observers an opportunity to ask the moderator to pose one final question to participants before the group’s end, and (4) a summary and the dissemination of information.
- ◆ The ordering of discussion guide questions should take into account participants’ need to get comfortable with each other.
- ◆ Work closely with the moderator to ensure sufficient time for the most important topics.
- ◆ Especially for groups about complex health issues, it is important to have an expert available to speak with participants after the discussion.
- ◆ Detailed notes, videotapes, debriefing sessions after groups, and transcripts all help you recall and analyze your findings.
- ◆ The type of report you write depends on how the information will be used, who the target audience is, what resources are available, and what logistic issues are involved.



## 4. *PRINT AND ELECTRONIC RESOURCES ON FOCUS GROUPS FOR FURTHER READING*

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### Print Resources

AMC Cancer Research Center. (1994). *Listening to your audience: Using focus groups to plan breast and cervical cancer public education programs*. Denver, Co.: AMC Cancer Research Center.

This handbook contains a wealth of useful information about how to plan focus groups on a health-related topic. It provides especially useful information about planning focus groups with low-income audiences.

Anderson, R.M., et al. (1996). Using focus groups to identify psychosocial issues of urban black individuals with diabetes. *The Diabetes Educator* 22:1, 28–33.

This article describes a focus group study in Detroit. Psychosocial issues identified in the groups were prioritized by an expert panel.

Krueger, R.A. (1994). *Focus groups: A practical guide for applied research*. Thousand Oaks, Calif.: Sage Publications. Phone: (805) 499-9774/Fax: (805) 499-0871.

This update of Krueger's well-respected 1988 textbook presents a step-by-step approach to planning and conducting a successful focus group, analyzing focus group results, and accounting for cultural diversity.

Krueger, R.A. (1997). *Developing questions for focus groups*. Thousand Oaks, Calif.: Sage Publications. Phone: (805) 499-9774/Fax: (805) 499-0871.

This paperback describes a process for developing questions and provides many examples of how to phrase and sequence focus group questions.

Krueger, R.A. (1997). *Involving community members in focus groups*. Thousand Oaks, Calif.: Sage Publications. Phone: (805) 499-9774/Fax: (805) 499-0871.

This book offers nonresearchers tips, advice, and exercises on conducting focus groups.

Krueger, R.A. (1997). *Moderating focus groups*. Thousand Oaks, Calif.: Sage Publications. Phone: (805) 499-9774/Fax: (805) 499-0871.

#### 4. Print and Electronic Resources on Focus Groups for Further Reading

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This text provides an overview of critical skills needed by moderators, approaches that successful moderators use, and strategies for handling difficult situations.

Morgan, D.L. (1997). *Focus groups as qualitative research*, 2nd ed. Thousand Oaks, Calif.: Sage Publications. Phone: (805) 499-9774/Fax: (805) 499-0871.

This book discusses the uses of focus groups, including their strengths and weaknesses, as well as planning, designing, conducting, and analyzing focus groups.

National Cancer Institute. (1989). *Making health communications work*. NIH Publication No. 89-1493. Bethesda, Md.: U.S. Department of Health and Human Services, Office of Cancer Communications, National Cancer Institute.

This “classic” for health communication professionals provides an excellent overview of health communication theories as well as a primer on focus groups and other qualitative research techniques.

Steckler, A., McLeroy, K.R., Goodman, R.M, Bird, S.T., and McCormick, L. (1992). Toward integrating qualitative and quantitative methods: An introduction. *Health Education Quarterly* 19(1): 1–8.

This article highlights the strengths and weaknesses of the qualitative and quantitative paradigms and discusses how to combine the two approaches.

Stewart, D.W., and Shamadasani, P.N. (1990). *Focus groups: Theory and practice*. Thousand Oaks, Calif.: Sage Publications. Phone: (805) 499-9774/Fax: (805) 499-0871.

This book, now in its ninth printing, examines every aspect of focus groups, from selecting and recruiting participants to designing the moderator guide to analyzing the findings.

### Electronic Resources

First a few words on searching the Internet for information on focus groups. Searching on *focus groups* produces articles that almost always are about commercial market research, not health communication research. Although many of the principles of commercial market research are relevant, the goals and target audiences of health communication research tend to be quite different. In addition, searches also produce a large percentage of items that use the term *focus group* to mean groups that are centered around meditation or self-exploration, which are not relevant for health communication research.

Center for Substance Abuse Prevention. (1994). *Technical assistance bulletin: You can manage focus groups effectively for maximum impact*. Internet: <http://www.health.org/govpubs/MS495/>.

This concise bulletin offers step-by-step instructions for convening effective focus groups. It also offers case studies and a helpful reference list.

Center for Substance Abuse Prevention. (1994). *Technical assistance bulletin: Conducting focus groups with young children requires special considerations and techniques*. Internet: <http://www.health.org/govpubs/MS501/>.

This bulletin offers tips and techniques that can make focus groups with children—or with any other group—run smoothly.

Feig, B. (1996). *Focus groups: They're not just for researchers anymore*. Internet: <http://www.businessknowhow.com/>.

Although this short article addresses using focus groups for commercial market research, the common pitfalls that it outlines are also applicable to health communication research.

Greenbaum, T. (1996). *The focus group bill of rights*. Internet: <http://www.groupsplus.com/rights.htm>.

This document outlines a “bill of rights” for clients, moderators, facility operators, and respondents.

Greenbaum, T. (1996). *Making it work for you behind the one-way mirror*. Internet: <http://www.groupsplus.com/mirror.htm>.

This article offers focus group observers seven tips for making groups more productive. Examples include writing down the most important things you want to learn and focusing on the big picture rather than the comments of one or two group members.

Market Navigation, Inc. (1997). Home Page. Internet: <http://www.mnav.com>.

This home page features links to the following articles about qualitative market research:

*Client guide to the focus group*. Internet: <http://www.mnav.com/cligd.htm>.

This article discusses issues such as when to use focus groups and offers tips on managing focus group projects.

#### ***4. Print and Electronic Resources on Focus Groups for Further Reading***

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*How to get beneath the surface in focus groups.* Internet:  
<http://www.mnav.com/bensurf.htm>.

Topics covered include recruiting participants, eliciting the most valuable information during groups, and group dynamics.

*How to get more out of your focus groups.* Internet:  
<http://www.mnav.com/getmore.htm>.

Common pitfalls in focus group projects are addressed.

*Everything in moderation.* Internet: <http://www.mnav.com/>.

This article discusses how to pick a moderator versus a qualitative research consultant. Skills needed for both are identified.

New York Chapter, American Marketing Association. (annual editions). *GreenBook and focus group directory*. Internet:  
<http://www.greenbook.org>. Phone: (212) 687-3280/Fax: (212) 557-9242.

This “bible” of focus group facilities throughout the country is also available in print.

*Quirk’s researcher sourcebook, 1996–1997.* Internet:  
<http://www.quirks.com>.

This listing of more than 3,700 firms that provide marketing research services is organized by firm name, specialty, and geographic location.

Sage Publications, Inc., Home Page. Internet: <http://www.sagepub.com>.  
Phone: (805) 499-9774/Fax: (805) 499-0871.

This company publishes many of the most respected texts on focus groups and other qualitative research techniques.

U.S. Army Family Advocacy Program. (1996). *Marketing family advocacy: Using focus groups to create excellence*. Internet:  
<http://child.cornell.edu/army/focus.html>.

This six-page handbook answers basic questions such as “What are focus groups?” “How are the interviews structured?” “How is the information summarized?” and “When should you not use focus groups?”

## **5. ARTICLES USED IN BACKGROUND RESEARCH FOR THE DIABETES PREVENTION MARKETING STUDY**

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This section lists articles in the following categories:

- ◆ General diabetes-related articles
- ◆ General and diabetes-related articles about racial/ethnic minority populations
- ◆ Diabetes-related articles about American Indians
- ◆ Diabetes-related articles about Hispanics/Latinos
- ◆ Diabetes-related articles about African Americans
- ◆ Diabetes-related articles about Asian Americans

### **General Diabetes**

American Diabetes Association Committee on Professional Practice. (1991). Standards of medical care for patients with diabetes mellitus. *Diabetes Spectrum* 4: 297–301.

Anderson, R.M. (1993). Assessing patient attitudes about diabetes: Implications for health-care professionals. *Diabetes Spectrum* 6: 150-151.

Benzaia, D., Jewler, D., Warren, J.C., and Keegan, A. (1992). Highlights from the American Diabetes Association's 52nd annual meeting and scientific sessions. *Diabetes Spectrum* 5: 256, 259.

Dawson, L.Y. (1993). The diabetes index: A national study of diabetes resources. *Diabetes Spectrum* 6: 138–142.

Fuqua, L. (1989). Marketing and diabetes education: 'A harmonious chorus.' *Diabetes Educator* 15: 210–213.

Lobovitz, H.E. (1993). From research to practice: Conclusions. *Diabetes Spectrum* 6: 131–132.

Moody, L.E., and Laurent, M. (1984). Promoting health through the use of storytelling. *Health Education* 15: 8–12.

Mount, M.A., Kendrick, O.W., Draughon, M., Stitt, K.R., Head, D., and Mount, R. (1991). Group participation as a method of achieving weight loss and blood glucose control. *Journal of Nutrition Education* 23: 25–29.

Pugh, J., and Stern, M.P. (1992). The importance of epidemiology for the prevention of diabetic complications. *Diabetes Spectrum* 5: 88–89.

## Minority Populations

Wilson, R., and Horton, E. (1993). Workshop report: Prevention and early treatment of NIDDM. *Diabetes Care* 16: 376–377.

Anderson, J.M., Blue, C., and Lau, A. (1993). Women's perspectives on chronic illness: Ethnicity, ideology and restructuring of life. *Diabetes Spectrum* 6: 102–112.

Bertorelli, A.M. (1990). Nutrition counseling: Meeting the needs of ethnic clients with diabetes. *The Diabetes Educator* 16: 285–289.

Davidson, J.A. (1991). Diabetes care in minority groups: Overcoming barriers to meet these patients' special needs. *Postgraduate Medicine* 90: 153–168.

Davidson, J.A., Jewler, D., Lipson, L.G., Kato-Palmer, S., Boggs, W.L., Moore, D., Pope, A., and Brosseau, J.D. (1988). Diabetes: An equal opportunity disease. *Diabetes Forecast* 41: 26–51.

Eaton, C. (1977). Diabetes, culture change, and acculturation: A biocultural analysis. *Medical Anthropology* 1: 41–63.

Geist, P. (1994). Negotiating cultural understanding in health care communication. In L. Samovar and R.E. Porter, eds. *Intercultural communication: A reader* (7th ed.). Belmont, Calif.: Wadsworth.

Hawthorne, K., Meool, M., and Tomlinson, S. (1993). Cultural and religious influences in diabetes care in Great Britain. *Diabetic Medicine* 10: 8–12.

Hendricks, R.T., and Hass, L.B. (1991). Diabetes in minority populations. *Nurse Practitioner Forum* 2: 199–202.

Howe-Murphy, R., Ross, H., Tseng, R., and Hartwig, R. (1989). Effecting change in multicultural health promotion: A systems approach. *Journal of Allied Health* 18: 291–305.

Kittler, P.G., and Sucher, K.P. (1990). Diet counseling in a multicultural society. *Diabetes Educator* 16: 127–131.

Lieberman, L.S. (1987). Cultural sensitivity and problems of interethnic communication. *Directions in Applied Nutrition* 1: 5–6.

- Lindquist, G.J. (1990). Integration of international and transcultural content in nursing curricula: A process for change. *Journal of Professional Nursing* 6: 272–279.
- Luyas, G.T. (1991). An explanatory model of diabetes. *Western Journal of Nursing Research* 13: 681–697.
- Murphy, F.G., Satterfield, D., Anderson, R.M., and Lyons, A.E. (1993). Diabetes educators as cultural translators. *Diabetes Educator* 19: 113–118.
- O'Brien, T.R, Flanders, W.D., Decoufle, P., Boyle, C.A., DeStefano, F., and Teutsch, S. (1989). Are racial differences in the prevalence of diabetes in adults explained by differences in obesity? *JAMA* 262: 1485–1488.
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- Stein, H.F. (1992). The many-voiced cultural story line of a case of diabetes mellitus. *Journal of Family Practice* 35: 529–533.
- Waxler-Morrison, N., Anderson, J.M., and Richardson, E., eds. (1990). *Cross-cultural caring: A handbook for health professionals in western Canada*. Vancouver, B.C.: University of British Columbia Press.
- Winkleman, E.A. (1990). Who's watching the kids? Diabetes and inner city children. *Diabetes Spectrum* 3: 73–78.

## American Indians

- Acton, K., Valway, S., Helgersen, S., Huy, J.B., Smith, K., Chapman, V., and Gohdes, D. (1993). Improving diabetes care for American Indians. *Diabetes Care* 16: 372–375.
- Boyce, V.L., and Swinburn, B.A. (1993). The traditional Pima Indian diet. *Diabetes Care* 16: 369–371.

- Broussard, B.A., Bass, M.A., and Jackson, M.Y. (1982). Reasons for diabetic diet noncompliance among Cherokee Indians. *Journal of Nutrition Education* 14: 56–57.
- Doughty, R. (1994). Indian health service stages battle against Type II diabetes. *Living Well with Diabetes* 9: 6–11.
- Gohdes, D., and Bennett, P.H. (1993). Introduction: Diabetes in American Indians and Alaskan Natives. *Diabetes Care* 16: 214–215.
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- Hosey, G.M., and Freeman, W.L. (1990). Designing and evaluating diabetes education material for American Indians. *Diabetes Educator* 16: 407–414.
- Huttlinger, K., Krefting, L., Drevdahl, D., Tree, P., Baca, E., and Benally, A. (1992). Doing battle: A metaphorical analysis of diabetes mellitus among Navajo people. *American Journal of Occupational Therapy* 46: 706–712.
- Judkins, R.A. (1978). Diabetes and perception of diabetes among Seneca Indians. *New York State Journal of Medicine* 78: 1320–1323.
- Justice, J.W. (1989). Twenty years of diabetes on the Warm Springs Indian Reservation, Oregon. *American Indian Culture and Research Journal* 13: 49–81.
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- MacDonald, F., Shah, W.M., and Campbell, N.M. (1990). Developing strength to fight diabetes: Assessing the education needs of Native Americans with diabetes mellitus. *Beta Release* 14: 13–16.

Miller, P., Wikoff, R., Keen, O., and Norton, J. (1987). Health beliefs and regimen adherence of the American Indian diabetic. *American Indian and Alaskan Native Mental Health Research* 1: 27–39.

Newman, B.L. (1993). A diabetes camp for Native American adults. *Diabetes Spectrum* 6: 166–202.

Newman, W.P., Hollevoet, J.J., and Frohlich, K.L. (1993). The diabetes project at Fort Totten, North Dakota, 1984–1988. *Diabetes Care* 16: 361–363.

Orr, A.L. (1993). Training outreach workers to serve American Indian elders with visual impairment and diabetes. *Journal of Visual Impairment and Blindness* 87: 336–340.

Stegmayer, P., Lovrien, F.C., Smith, M., Keller, T., and Gohdes, D.M. (1987). Designing a diabetes nutrition education program for a Native American community. *Diabetes Educator* 14: 64–66.

Stracqualursi, F., Rith-Najarian, S., Hosey, G., and Lundgren, P. (1993). Assessing and implementing diabetes patient education programs for American Indian communities. *Diabetes Educator* 19: 31–34.

Weiler, C. (1990). Amber White Bear: Working to increase awareness. *Living Well with Diabetes* 5: 9–13.

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Womack, R.B. (1993). Measuring the attitudes and beliefs of American Indian patients with diabetes. *Diabetes Educator* 19: 205–209.

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Adams, R., Briones, E.H., and Rentfro, A.R. (1992). Cultural considerations: Developing a nursing care delivery system for a Hispanic community. *Nursing Clinics of North America* 27: 107–116.

Brown, S.A., Duchin, S.P., and Villagomez, E.T. (1992). Diabetes education in a Mexican population: Pilot testing a research-based videotape. *Diabetes Educator* 18: 47–51.

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- Hall, T.A. (1986). Designing culturally relevant educational materials for Mexican American clients. *Diabetes Educator* 13: 281–285.
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- Schultz, L.O., and Weindensee, R.C. (1993). Non-insulin-dependent diabetes mellitus in Mexico. *Progress in Food and Nutrition Science* 17: 99–117.
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- Seijo, R., Gomez, H., and Freidenberg, J. (1991). Language as a communication barrier in medical care for Hispanic patients. *Hispanic Journal of Behavioral Sciences* 13: 363–376.
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Zaldivar, A., and Smolowitz, J. (1994). Perceptions of the importance placed on religion and folk medicine by non-Mexican-American Hispanic adults with diabetes. *Diabetes Educator* 20: 303–306.

Zonszein, J. (1993). Latinos and diabetes. *Diabetes Spectrum* 6: 88–137.

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Gavin, J.R., and Goodwin, N. (1990). Diabetes in Black populations: Current state of knowledge. *Diabetes Care* 13 (11 Supplement 4): 1140–1142.

Kumanyika, S.K., and Ewart, C.K. (1990). Theoretical and baseline considerations for diet and weight control among Blacks. *Diabetes Care* 13: 1154–1162.

McNabb, W.L. (1994). Delivering more effective weight-loss programs for Black American women. *Diabetes Spectrum* 7: 332–333.

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Pi-Sunyer, F.X. (1990). Obesity and diabetes in Blacks. *Diabetes Care* 13: 1144–1149.

Raymond, N.R., and D’eramo-Melkus, G. (1993). Non-insulin-dependent diabetes and obesity in the Black and Hispanic population: Culturally sensitive management. *Diabetes Educator* 19: 313–317.

Reid, B.V. (1992). It’s like you’re down on a bed of affliction: Aging and diabetes among Black Americans. *Social Science Medicine* 34: 1317–1323.

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Weiner, D. (1991). Trent Tucker contributes on and off the court. *Living Well with Diabetes* 6: 7–8.

## Asian Americans

- Burden, A.C., Samanta, A., and Rahman, F. (1988). Customs, mores and diabetics: Lessons from the Indian diabetic. *Practical Diabetes* 8: 224–226.
- Doughty, R. (1994). Another view of China's Great Wall. *Living Well with Diabetes* 9: 5–7.
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# ***APPENDIX A: DIABETES PREVENTION MARKETING STUDY EXECUTIVE SUMMARY***

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## **BACKGROUND AND PURPOSE OF THE STUDY**

While approximately 8 million Americans have been diagnosed with diabetes, at least double that number may suffer from this disease unknowingly. As the seventh leading cause of death in 1993, diabetes mellitus accounts for significant morbidity, lost productivity, and premature mortality for many Americans, with a disproportionate burden borne by African Americans, Hispanics/Latinos, Native Americans, and Asian Americans. There are numerous strategies that people with diabetes and their health care providers can use to reduce the impact of the disease. However, the true potential of prevention strategies identified in the Diabetes Control and Complications Trial (DCCT) has not been realized.

Most research on diabetes is epidemiological in nature, clearly indicating numerically the great magnitude of the disease and its etiology. However, comparatively little research has been conducted to identify how knowledge, attitudes, beliefs, and behaviors contribute to diabetes-related disability and premature death. This discrepancy is particularly pronounced for racial/ethnic minority populations. In order to reduce the burden of diabetes, the Division of Diabetes Translation (DDT) has identified health communication as a key strategy. In order for health communication activities to have the greatest success, health educators and health care practitioners must recognize that there are a variety of potential audiences within any given population and that strategies that may work for one group will not necessarily be as helpful for another. Health communication experts have become especially sensitive to the knowledge, attitude, belief, and behavior differences with regard to health issues that exist among the various cultural groups within this country.

To communicate most effectively with people from different backgrounds and cultures, health professionals must strive to step back and understand the health issue from the perspective of those who are affected themselves. There are a variety of research methods available to those wishing to understand behavioral aspects of diabetes. One method that provides one of the richest sources of data is focus group research. Although findings are not generalizable, focus groups offer an opportunity to hear about people's thoughts and experiences in detail directly from the people themselves.

The Diabetes Prevention Marketing Study focused on people with non-insulin-dependent diabetes mellitus (NIDDM) in four minority populations: African Americans, Hispanics/Latinos, American Indians, and Asian Americans. The project's purpose was twofold:

1. To gather information from individuals in minority populations that adds to the existing knowledge base. The information gathered would help those interested in further researching diabetes in minority

populations to have some context for understanding the issues and problems affecting certain groups. Also, the information gathered can provide researchers with a starting point for their own research and communication efforts.

2. To provide practical and applicable information about conducting focus groups in minority communities.

### **FOCUS GROUP PARTICIPANTS' CHARACTERISTICS AND LOCATIONS**

Focus groups were held with African American participants, Asian American participants representing several different countries of origin, Hispanic/Latino participants also representing several countries of origin, and Native American participants from various tribes. The participants were invited to join the focus groups based on the following criteria:

- Having Type 2 diabetes, diagnosed after age 30
- Being between the ages of 40 and 70
- Earning an annual household income of less than \$20,000 (low-income groups) or \$20,000 to \$50,000 (middle-income groups)

A total of 27 groups were held in 12 different locations during a period lasting from June 1995 to October 1996. The 12 locations listed in Table 1 were selected for several reasons, including demographic characteristics of the populations and geographic variety. The research team wanted to hear from people across the nation living in various settings ranging from inner city to very rural. Because few databases of people with diabetes exist, the research team relied upon the assistance of local contacts who could provide means for reaching particular populations.

**Table 1. Focus group locations and group composition**

Location	Ethnicity	Gender	SES level	Language
<b>Montana</b>				
Blackfeet Indian Reservation	Native American	mixed	not screened	English
	Native American	mixed	not screened	English
Flathead Indian Reservation	Native American	mixed	not screened	English
Northern Cheyenne Reservation	Native American	women	not screened	English
	Native American	men	not screened	English
Missoula	Native American	mixed	not screened	English
<b>Wyoming</b>				
Wind River Reservation, Shoshone Community	Native American	women	not screened	English
Wind River Reservation, Arapaho Community	Native American	men	not screened	English
<b>Los Angeles, CA</b>				
	Mexican and Central American	women	low	Spanish
	Mexican and Central American	men	low	Spanish
	Korean	women	middle	Korean
	Korean	men	middle	Korean
	Filipino	mixed	middle	Tagalog
	Vietnamese	mixed	low	Vietnamese
<b>Ashburn, GA</b>				
	African American	mixed	low	English
<b>Minneapolis, MN</b>				
	Native American (various tribes)	mixed	not screened	English
<b>New York, NY</b>				
	Hispanic/Latino (Dominican and Puerto Rican)	women	low	Spanish
	Latino (Dominican and Puerto Rican)	men	low	Spanish
	Asian (Chinese Mandarin)	mixed	low	Mandarin
	Asian (Chinese Cantonese)	mixed	middle	Cantonese
<b>Chicago, IL</b>				
	African American	mixed	low	English
	African American	mixed	middle	English
<b>Houston, TX</b>				
	Mexican American	men	low	Spanish
	Mexican American	women	low	Spanish
	African American	mixed	middle	English
	African American	mixed	low	English
	African American	mixed	low	English

## TOPICAL DISCUSSION

The moderators' guide for the topical discussion was designed to promote open communication among participants and the moderator. Topics relevant to the study were selected for exploration during the focus groups. The broad categories are shown in Table 2.

**Table 2. Moderators' guide discussion topics**

Main topics included:
<b>Background</b> - Discussion centered on how participants reacted when they were diagnosed with diabetes, their perception of the seriousness of the disease, why they are or are not able to successfully manage the disease, and the perception of diabetes in their community.
<b>Sources of information</b> - Various communication channels and their credibility were discussed.
<b>Health care</b> - Participants related their experiences with obtaining and paying for medical help for their diabetes. The moderator also asked them about any alternative methods or remedies they use to treat their diabetes.
<b>Personal and family experience</b> - Participants were asked how their family affects the management of their disease, the effects of stress, and the type of family and community support they receive.
<b>Food plan and exercise or physical activity</b> - This part of the discussion focused on the problems the participants encounter with maintaining prescribed food plans and the barriers that prevent them from engaging in regular exercise or physical activity.

## SYNOPSIS OF CONTENT FINDINGS

The Diabetes Prevention Marketing Study revealed a wide range of information about people's thoughts about and experiences with diabetes. A brief sample of those findings is presented below. The findings are discussed for each racial/ethnic group in turn.

### **Findings from Focus Groups with African Americans**

Focus groups were held with African American participants in Ashburn, Georgia; Chicago, Illinois; and Houston, Texas.

- While some participants in these groups reported having experienced the warning signs for diabetes, few recognized them at the time. Among the symptoms respondents listed were excessive fatigue, constant thirst, numbness or tingling of feet, and obesity. Even among those respondents who indicated a genetic predisposition toward diabetes, few said they had done anything to protect themselves prior to the onset

of the disease. The existence of a genetic predisposition toward diabetes seemed to induce fear and, for many, the desire to simply ignore it.

- Virtually none of the respondents in the African American groups said they felt prepared for the life changes that followed their diagnosis, and many expressed grave concerns about having diabetes. They were especially concerned about blindness, amputation, high blood pressure, stroke, heart attack, and self-administered injections.
- Confusion and concern existed around the term *borderline diabetes*. Some respondents had been told that there was no such thing—that you either had diabetes or did not. Others thought it meant never *really* having diabetes. Still others thought it meant that diet, not medication, was the treatment. There was also confusion as to the probability of making diabetes disappear by properly adhering to medical guidelines.
- There was a strong belief among participants that the incidence of diabetes was higher in the African American community than in other groups. It was suggested that there are probably thousands of African Americans who have diabetes and should receive medical care but are unaware that they have it. Some respondents felt that although people may know of diabetes, more emphasis should be placed on its warning signs and the seriousness of the disease. Additionally, many said that because African Americans tend to put off seeking health care, diabetes may be discovered late.
- When asked about good locations for disseminating information about diabetes, participants stated that workshops were helpful. Some respondents had seen and liked diabetes-related videos. Word-of-mouth information from family members, friends, and coworkers was mentioned, but the accuracy of that information was not particularly trusted. These African American participants listed various potential distribution points for information about diabetes, including schools, beauty and barber shops, grocery stores, health fairs at churches and other key community sites, radio, television, and newspapers. Family reunions were mentioned as a setting in which large numbers of people (200 in one case) were gathered and could be reached with pertinent information about diabetes or even about their own family's history of diabetes.

### **Findings from Focus Groups with Asian Americans**

Groups were held separately with Chinese, Korean, Filipino, and Vietnamese participants. Some of the cross-cutting findings as well as the differences among groups are listed below.

- Many of the Asian participants reported that they had a very negative initial reaction to their diagnosis. Responses included fear, anxiety, worry, disbelief, depression, anger, sadness, and self-reproach. There

were a number of participants, however, who described reactions that were less negative. For example, some minimized the seriousness of diabetes. Others took the view that diabetes was preordained to be part of their lives, so they felt no choice but to accept it.

- In most Asian groups studied, respondents believed diabetes was caused by a combination of factors, including particularly intense emotional stress, the consumption of sweets, and heredity. Chinese, Vietnamese, and Filipino participants did not seem to feel that diabetes was more common among members of their own ethnic groups.
- Chinese participants felt that their diet did not lend itself to developing diabetes, stating that they consumed foods low in fat and low in sugar. However, the Korean participants believed that there is a high incidence of diabetes among their countrymen. They spoke of the Korean diet, pointing to an emphasis on meat and spicy foods. They also felt that more sweet foods are available in the United States than in Korea. They also attributed the higher incidence of diabetes among Koreans in the United States to the fact that Koreans exercise less in the United States than they did in their homeland.
- Several worried about the impact that diabetes could have on their interactions with others. They explained that among Asian people there is a strong focus on the group's harmony and well-being, as opposed to an individual's well-being. Thus, Asians do not want to stand out from the crowd. To do so would create embarrassment, said participants. They also pointed out that they do not want to embarrass their hosts by not eating what is served at social gatherings.
- Family support was particularly important among the Asian participants. In describing the role of the family in diabetes treatment, most of the respondents described their families as supportive.
- Many Chinese participants stated that both Western doctors and Chinese herbal doctors participate in their health care. The herbal doctors were valued by participants in part because they speak the same language and understand their culture and eating habits. Overall, herbal doctors were perceived as taking the time to explain to their patients the etiology of diabetes and preventative/maintenance measures.
- Similar to reports in the literature, daily in-language newspaper readership among the Asian participants was very high. Thus, in-language newspapers may be an excellent source of information for these populations.

### **Findings from Focus Groups with Hispanics/Latinos**

The Hispanic/Latino populations in this study included Central Americans, Mexicans, Puerto Ricans, and Dominicans. These participants varied in their length of residency in the United States.

- Most of the Hispanic/Latino participants were diagnosed with diabetes while in the United States. Their reactions ranged from denial to fear and anxiety. On one hand, some respondents indicated that they denied their illness. On the other extreme, some people felt very depressed and hopeless. Many of these respondents associated diabetes with the death of a family member, which exacerbated their own feelings of hopelessness and depression.
- Participants expressed enormous concern for their families, for whom they were providing economic support. They were very worried about losing their ability to provide for their loved ones.
- When discussing why some Hispanics/Latinos might not manage their diabetes well, participants pointed to a lifestyle that emphasizes the joys and pleasures of eating. One respondent said, “Comemos para gosar, no para nutrarnos” (*We eat to enjoy, not for nutritional reasons.*). “Vivimos para comer y no comemos para vivir” (*We live to eat, and not only to help us survive.*).
- Participants in all cities stated that they received information about diabetes from brochures given to them by their doctors in hospitals and clinics. The brochures were in both English and Spanish. Respondents also stated that educational programs on television and radio, particularly Spanish-language television, play an important role in providing them with information about the symptoms and treatments for diabetes. Informal conversations with others who had diabetes was a major source of information for these participants. In addition, newspapers played a role in informing these respondents about diabetes. However, the in-language press was not nearly as important for these Hispanic/Latino participants as it was for Asian participants. Videos and lectures were named as helpful, but were not commonly mentioned sources.
- Latino participants said having bilingual information is very important. Most said they feel more comfortable speaking Spanish and that they would feel that they had a better understanding, especially of health issues, if the information was available in Spanish. The respondents encountered difficulty because some information is provided only in English.

### **Findings from Focus Groups with Native Americans**

Respondents reported that they refer to themselves as Native American, Native People, and Indian. Thus, these terms are used interchangeably in this report. The Native Americans studied in this research included members of the following tribes: Salish, Kootenai, Pend D’oreille, Blackfeet (Piekuni), Sioux, Red Lake, Molack, Chippewa, Arapaho, Shoshone, and Northern Cheyenne.

- Participants said they felt fearful at the news of their diabetes and worried for their future. This related to concerns about living with and dying from a chronic disease. As was the case with the other ethnic

groups studied, many Native American participants were also fearful of the pain they would experience from insulin injections.

- As with other ethnic groups in this study, food and culture are closely related and have an impact on a person's ability to manage his or her disease. People with diabetes stated that they often have difficulty eliminating from their diet traditional foods that do not fit into a diabetes food plan. Some Native American participants expressed that this may be a reason diabetes is not well managed.
- Alcohol consumption and the expense associated with many healthy foods (e.g., fresh fruits and vegetables, low-fat meats) were also named by participants as factors that negatively impact the management of diabetes. In addition, these Native Americans said that the food commodities supplied by the government are often unhealthy, especially for people with diabetes.
- Many respondents felt that they lacked information about diabetes. The respondents, particularly those in Minneapolis and Wyoming, suggested that diabetes information be provided in-language (Chippewa, Sioux, Ojibeway). In-language diabetes information was said to be especially necessary because the elderly, many of whom live in isolated situations and/or are resistant to visiting health care providers, often do not understand English.
- With the exception of the Shoshone and the Arapaho, most respondents felt that the ethnicity of the treating physician did not need to be the same as that of the Indian patient with diabetes. However, they did feel that a Native American doctor would put an Indian patient at ease, would take more time with the examination, and would be more patient and thorough in answering questions. For example, Native Americans establish social relationships with other individuals by identifying people they might know, have in common, or be related to by their tribal origin. Indian doctors were said to understand this practice and, therefore, to engage in this type of discussion with their patients. Most respondents believed that non-Indian doctors who treated Native Americans should be required to study the history and culture of Native Americans. This study should include first-hand experience of some Indian rituals, including the sweat lodge; study about the influence of European settlement on Native American lifestyles and traditional practices; information about contemporary eating habits of Native Americans; and insight into Indian culture, such as the tendency not to interfere and the reluctance to ask questions (i.e., gathering information from observation over time, as opposed to obtaining information via questioning).

## **SYNOPSIS OF PROCESS FINDINGS**

To promote and support further focus group research, the second purpose of this study was to use the knowledge we gained in our research effort in a variety of settings to develop practical tips and advice on conducting focus groups with minority populations for health practitioners, health educators, and other researchers. A few examples of the lessons we learned are noted below.

- For any population that you study, always show your appreciation by finding ways to “give back” to the community. The communities and participants you study are not merely potential sources of data. They have invited you into their community and allowed you to ask personal questions of their friends, relatives, neighbors. To reciprocate this favor, researchers should make every possible attempt to include communities members in the research process. For example, whenever possible researchers should stay in a local hotel, eat at local restaurants, hire local businesses or individuals to record the focus group proceedings or provide food, and, if invited, take part in community activities during their visit. Local contacts and research partners are tremendous assets, and researchers should provide them with the results of the study in their community. This is not only a courtesy in return for their cooperation and help; it also is a way to maintain good relationships for future health promotion efforts or research.
- There are many creative ways to go about identifying and recruiting possible participants for your focus group with hard-to-reach populations. The most obvious source is the databases of professional market research firms; however, these firms are generally geared toward commercial businesses, not people who are conducting research on health issues. If such databases do not meet your needs, or if you are not using a professional firm at all, you should identify community organizations, community health clinics, or other community contacts who have access to the populations you want to study.
- Your moderator may be able to provide you with a cultural frame for interpreting focus group process and outcomes. Before and after each focus group, ask the moderator to alert researchers to issues or situations that may impact the group’s discussion or that researchers should take into consideration when interpreting the data. The input of one moderator was particularly valuable with one Korean focus group whose participants were unusually reserved. The moderator explained later that because one participant was a pastor, the other participants yielded the floor to him whenever he made a comment out of a sense of respect. This information helped put the group’s dynamics into context and alerted researchers that acquiescence of the floor did not necessarily indicate that participants agreed with the pastor’s points.
- If a professional focus group facility is not practical for your budget or feasible as a meeting place for your participants, consider sites such as community centers, churches, and elementary schools. At such sites, observing the focus group from another room using a closed-circuit television is a good option, because observers will not be distracting or unsettling to participants. If a closed-circuit television is not a viable option, it is acceptable, though not preferable, to observe your participants from the same room in which the focus group is taking place. In this case, observers should be sensitive to the possible apprehensions participants might feel about being watched. To allay concerns, moderators should introduce the observers to participants. In any event, the presence of observers must always be disclosed to participants.
- Consider how the culture of the participants will affect the dynamics of the group. For example, discussions may not be as fruitful if you mix people of different genders, ages, or social status. Partners

who work closely with the group you are researching can offer insights into relevant cultural patterns of the people you plan to work with in your study.

- When screening a community for participants in harder-to-reach populations, you may have to relax your screening criteria to find enough participants to fill a focus group. For example, in this study, researchers began with criteria perceived as ideal for meeting their research needs. But they soon realized that certain questions on the participant screener severely limited the recruiters' ability to find participants. By relaxing or eliminating criteria that were not as essential to the study's purpose, researchers were able to fill the groups and still conduct effective research.
- The opening questions of the discussion guide should be neutral and easy to answer and should illustrate to the participants the similarities among everyone in the focus group. For example, the moderator could ask participants to introduce themselves and relate when they learned they had diabetes. Questions such as, "What do you do for a living?" should be avoided. Such questions can set up a hierarchy among the participants and negatively affect the dynamics of the group.
- Be prepared to consider services participants may need, such as child care and transportation. Researchers should be prepared to arrange child care services at the facility for the duration of the focus group. If you decide not to provide child care, let participants know at the time of the screening that they will have to arrange for child care on their own. Consider arranging a bus service, reimbursing participants for cab fare, or finding other means of transporting participants to and from the session.
- Be prepared to accommodate spouses, friends, or relatives who may accompany the participants by providing meals and a comfortable place for them to wait while the group is in session.
- Consider in your planning the physical discomforts the participants may be experiencing. For example, some people with diabetes have low stamina. Be sure to provide comfortable chairs and plenty of liquid refreshments.
- Do not allow your subjects to walk away from a focus group with incorrect information. Sometimes participants are confused about the topics being discussed. Often, erroneous information is raised by participants during the session. Have an expert on hand to observe the groups and join participants afterward to clarify misinformation. Participants should also be allowed to ask the expert questions. At a minimum, have culturally appropriate educational material available for distribution and a list of sources of additional information.

# **APPENDIX B:**

## **FOCUS GROUP SCREENER FOR**

### **DIABETES PREVENTION MARKETING STUDY**

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Name: \_\_\_\_\_

Address: \_\_\_\_\_

City/Zip Code: \_\_\_\_\_

Phone Number: \_\_\_\_\_

Hello. My name is \_\_\_\_\_ from \_\_\_\_\_. We are conducting a study about health care among Native Americans in your area. We are not selling anything. We just want to learn your opinions about certain types of health care. Your opinions will help us greatly in this study. This will only take a few minutes.

1. What is your ethnic origin?

Native American .....1 [CONTINUE]

Other..... [TERMINATE AND TALLY]

2. Do you or does anyone in your family have diabetes?

Yes.....1 [IF RESPONDENT DOES NOT HAVE DIABETES, ASK TO SPEAK TO THE PERSON WHO HAS IT. START WITH Q.1 AGAIN.]

No..... [TERMINATE AND TALLY]

3. Is your age [READ ANSWERS]

Under 40 years old..... [TERMINATE]

40–55 years old.....2 [CONTINUE]

56–70 years old.....3 [CONTINUE]

Over 70 ..... [TERMINATE]

4. At what age did you discover you had diabetes?

Under 30 years old..... [TERMINATE]

Over 30 years old.....1 [CONTINUE]

5a. Did you prick your finger to check your blood sugar one or more times in the last 24 hours?

No.....1 [CONTINUE]

Yes..... [TERMINATE]

**Appendix B**

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5b. [FOR INFORMATION ONLY. PLEASE CIRCLE ANSWER.]

Which of the following sentences best describes you?

1. Within the next month, I plan to start checking my blood sugar every day.
2. Within the next six months, I plan to start checking my blood sugar every day.
3. I do not intend to start checking my blood sugar in the next six months.

We will be holding a small discussion group with Native Americans like yourself to better understand your needs and to improve service to those who have diabetes. You will receive \$50 for your participation. Refreshments will be served. They will be prepared according to your special dietary needs. This discussion will be held at

\_\_\_\_\_.

6. Can you attend?

Yes.....1 [CONTINUE]

No..... [THANK AND TERMINATE]

7. Will you need assistance with a baby sitter?

Yes.....1 [RECORD NUMBER OF CHILDREN  
AND THEIR AGES BELOW]

No.....2 [THANK AND CONTINUE]

8. Will you need assistance with transportation?

Yes.....1 [SAY WE WILL HAVE THAT  
INFORMATION IN YOUR  
CONFIRMATION LETTER]

No.....2 [THANK THEM AGAIN AND  
CONTINUE WITH INFORMATION  
ABOUT THE CONFIRMATION LETTER]

You will receive a confirmation letter with directions and other important information soon. Thank you for accepting our invitation. Your opinions will be valuable for our research.

\_\_\_\_\_  
Recruiter

\_\_\_\_\_  
Date

\_\_\_\_\_  
Confirmed by

\_\_\_\_\_  
Date

[RECORD BABY SITTING INFORMATION HERE]

# of children: \_\_\_\_\_ Ages of children: \_\_\_\_\_

## APPENDIX C:

# SAMPLE DISCUSSION GUIDE QUESTIONS

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This appendix features some starter questions and tools or exercises that you might want to consider for your groups. Questions are tailored for three major types of focus groups:

- ◆ Focus groups designed to gain information related to participants' awareness, knowledge, attitudes, and beliefs about a particular topic or set of topics.
- ◆ Groups designed to obtain participants' reactions to specific concepts, prototype materials, or program plans.
- ◆ Groups whose purpose is to obtain participants' feedback after materials or program activities have been in place for a period of time.

<p><b>Sample Questions For...</b> <b>Learning about participants' awareness, knowledge, attitudes, and beliefs about a particular topic.</b></p>
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Focus groups to explore what participants know or believe about a particular topic or set of topics are often used to plan message concepts, materials, and program activities.

### Background:

Many discussion guides for this type of group use a tool or exercise as an ice-breaker to introduce the subject and stimulate general discussion. Examples include

***Handing out a newspaper article*** about the subject as participants arrive. Ask them to look over the clip before the group begins.

***Distributing a short questionnaire*** that asks people to rank a list of items according to each item's importance (e.g., life priorities such as having a happy family, good health, money, satisfying job). Choose a topic that is easy for people to have an opinion about so that they will not feel that their intelligence is being tested.

This ice-breaker serves two purposes. First, it gives participants specific material to react to, which can help smooth the early stages of the discussion while the group gets acquainted. Second, it gives the moderator an excellent tool to segue into discussions on the following points.

### General awareness and knowledge of topic:

*Tell me about what went through your mind as you looked over the article (or filled out the questionnaire).*  
(TIP: If a questionnaire is used, the moderator can ask whether someone will share his or her answers. Someone almost always does.)

*Have you ever thought about things like this before, or was this new to you?*

*Was there anything that you would say you particularly agree or disagree with?*

**Participants' sources for information about the topic:**

*Think back to times you have thought about this before and tell me about when and where you first started hearing about this topic. Was it in a newspaper? On TV? From friends?*

**Whether people need/want information about the topic:**

*Would you say that information about this is very interesting to you, somewhat interesting, or not very interesting? Tell me about why you feel that way. (TIP: It is usually not as revealing to ask people whether they think information is *important*. They know that "yes" is the answer you are looking for. They are more honest if you ask whether something is interesting.)*

*Does anyone have questions about this issue that new information should try to answer? (TIP: The moderator's job is to find out what questions people have, not to answer them.)*

*Why do you think people do/don't (eat healthy, exercise, take their medication....)? What makes it difficult for people to (eat well, exercise, take their medication....)? (TIP: Notice that this question is not phrased as the more accusatory, "Why don't YOU....?")*

*Are there some things you can think of that could make it easier for them to (eat well, exercise, take their medication....)?*

**Where/how information should be available:**

*How do you think information like this could be made more available to people?*

*Where do you think information about this should be available?*

*Are there particular times of the day, week, or year that might be better than others to tell people about this? When? What was your thinking on that?*

*If you heard about this from any of the following sources, which would you be most likely to believe? Moderator reads a list of specific organizations and/or sources such as "doctor," "friend," "church," or other potentially credible sources. (TIP: If the list is long, consider having this as a pencil/paper exercise. Use symbolic representations if your participants may have difficulty reading.)*

*Do you have any other advice about what should or should not be done to help people learn about this?*

<p style="text-align: center;"><b>Sample Questions For...</b> <b>Obtaining participants' reactions to specific concepts, prototype materials, or program plans.</b></p>
---

Suppose you have prepared preliminary message concepts, materials, or program plans and want to find out whether you are on the right track by getting some reactions from your target audience. Focus groups are often used for this purpose.

**Background:**

First, participants need to gain enough of an idea about your plans to respond with their opinions and suggestions. To do this, you might show them a foam-core board featuring key messages in block print; a mock-up of a brochure with draft text and graphics; preliminary artwork for an advertisement; storyboards or drawings of some planned footage for a video; or draft press releases or fact sheets. Or, you might play an audiotape of a radio spot or of several possible theme songs for a campaign.

You could begin with a short version of some of the same types of questions that are outlined above for learning about knowledge, attitudes, and beliefs, to confirm what you expected or reveal new issues. The moderator then will be able to address those points as participants view the materials. Then materials are introduced—and possibly tools for helping people provide their feedback, such as a “report card” handout for people to “grade” one or more features of what they review. Or, the moderator could ask half of the group to explain the main message of the information the group read to the other half.

Appropriate questions usually focus on

**General open-ended reactions:**

*Tell me what you thought when you first looked at this.*

*Was your first reaction generally positive, negative, or somewhere in between?*

*What would you say is the main idea of this information?*

**Whether the message(s) or information is credible:**

*When you read this information, did you believe it?*

*Were there some parts that seemed more or less true than others?*

*Was there anything that was new to you?*

*Is there a better way to say what is here?*

*Do you think other people would believe this?*

*Do you think anyone might do something different as a result of hearing about this?*

**Whether the artwork is appealing and engaging:**

*Would you say that your reaction to the way this looks was mostly positive, critical, or somewhere in between?*

*What did you like about it? Is there anything you think should be changed? What about the people featured? The way the words and pictures go together? The size of the words?*

**Where and when this is most likely to be noticed:**

*Do you think you would notice this if it was (on a cereal box, on television, at the dentist's office)?*

*Where do you think this should be available?*

*Where do you think people would notice something like this?*

*Are there other ways that you would try to get this information across to people?*

**Sample Questions For...**  
**Obtaining participants' feedback after materials and/or program activities have been in place for a period of time.**

Focus groups are also used to obtain feedback from people on how well things have worked after materials have been available or program activities have been implemented. To begin, many of the same types of questions (about participants' knowledge, attitudes or beliefs and reactions to materials) are asked in groups with this evaluation purpose. Then, additional questions are included to learn more about whether materials or activities influenced participants in some way and whether participants have suggestions or information needs that new materials and activities should incorporate. For example:

**Awareness and impact of materials/activities:**

**For materials . . .**

*Does anyone recall seeing this (message, ad, brochure, etc.) before? Where?*

*What went through your mind when you saw this?*

*Have you seen other information about this, but not this particular (brochure, ad, etc.)? (TIP: A question like this lets you compare recall of your materials to that of information from other sources.)*

**For activities . . .**

*Has anyone ever participated in the (blood drive, walkathon, volunteer program)?*

*Had you heard of it, but elected not to participate?*

*Is there anything you started doing differently after...*

**Suggestions for changing materials/activities:**

*Is there anything you would change about this . . .*

**For materials . . .**

*What it says? What changes to the wording are needed?*

*The way it looks? What might improve the way it looks?*

*Are there some places you think this should be available?*

*Anything that needs to go with it?*

**For activities . . .**

*What advice do you have about what could make this more interesting so more people will get involved?*

*Easier for them to get involved? (e.g., different time, location)*

Remember, these are just some ideas to get you started. The best questions will come from your research team and will be guided by your specific research purpose.

# ***APPENDIX D: DISCUSSION GUIDE***

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## **I. INTRODUCTION**

- Speak one at a time
- No right or wrong answers
- Audiotaping
- One-way mirror
- Confidentiality
- Respondents' introduction: name, where from, how/when they learned they had diabetes

Inform group that information discussed is going to be analyzed as a whole and that participants' names will not be used in any analysis of the discussion.

Topic discussed this evening is Type 2 diabetes.

**[IF NECESSARY, MODERATOR WILL EXPLAIN THAT THOSE WITH TYPE 2 DIABETES SOMETIMES NEED INSULIN]**

## **II. BACKGROUND**

- A. What was your reaction to the news that you had diabetes? Why?

**[PROBE: FEARS, CONCERNS, FEELINGS OF OPTIMISM, HELPLESSNESS]**

- B. What other names do people have for diabetes?

**[PROBE: ANY DIFFERENT WAYS OF DESCRIBING DIABETES IN THIS PARTICULAR ETHNIC/RACIAL GROUP]**

**[PROBE: FOR ANY OTHER METAPHORS FOR ILLNESS OR TREATMENT]**

- C. Do you worry about your diabetes? Why/why not?

**[PROBE: HOW SERIOUS OF A CONDITION DO RESPONDENTS PERCEIVE DIABETES TO BE?]**

- D. What are some reasons why people do not manage their diabetes well?

**[PROBE: LACK OF KNOWLEDGE, EXPENSE, LACK OF TIME, POOR ACCESS TO HEALTH CARE]**

**[PROBE: WHAT KEEPS YOU FROM BEING ABLE TO CONTROL YOUR DIABETES?]**

- E. Some people think there is not much they can do to control their diabetes. Why?

- F. Is there anything a person can do to keep from getting diabetes?

**[PROBE FOR EXAMPLES]**

- G. What are the benefits of keeping your blood sugar in control?
- H. Some people say that diabetes is more common among Native Americans than in the general U.S. population. Is this statement true or false?

How common is diabetes in this community? Why do you think so?

How do people in the community feel about diabetes?

**III. SOURCES OF INFORMATION**

- A. How much do you think other people in your community know about diabetes?

How do they learn about it?

Where do you/others in your community typically get information about diabetes?

**[PROBE: FOR SOURCES OF INFORMATION]**

- B. What problems have you encountered in getting helpful information about diabetes?
- C. How and where would you prefer to get information about diabetes?

Who/what is the most trustworthy source for information about diabetes in your community?

**[PROBE: TV, RADIO, VIDEO, PRINT, DIRECT MAIL, COMMUNITY HEALTH EVENTS, SUPPORT GROUPS, AT THE CLINIC, FROM THE DOCTOR, FROM THE CLERGYMAN, FEDERAL HEALTH AGENCIES SUCH AS THE CENTERS FOR DISEASE CONTROL AND PREVENTION AND THE NATIONAL INSTITUTES OF HEALTH, ORGANIZATIONS SUCH AS THE AMERICAN DIABETES ASSOCIATION, ETC.]**

- D. What diabetes messages do you think others like you need to know?

How do you suggest getting these messages across?

- E. Have you heard about a new study that showed how important it is to keep track of your sugars and keep them as close to normal as possible?

Where did you hear about this study?

**[PROBE FOR REACTION TO STUDY]**

- F. What do doctors and health care providers not understand about the Native American community and its experience with diabetes?

- G. How does your health care provider's ethnic or racial group affect his or her ability to help you with your diabetes?

When you visit the doctor, are there things that you would like to discuss that he or she does not ask about?

**[PROBE FOR EXAMPLES]**

IV. HEALTH CARE

- A. Where do you get help for your diabetes?

Please tell me some positive and negative experiences you've had getting help.

**[PROBE BOTH POSITIVE AND NEGATIVE EXPERIENCES]**

- B. What, if anything, keeps you from receiving help for your diabetes?
- C. Are you able to obtain the care you need to manage your diabetes? (e.g., medicines, glucose testing strips)
- D. Are there other ways that diabetes is treated in the Native American community?

**[PROBE TRADITIONAL WAYS OR HERBAL REMEDIES]**

Do you know anyone who has ever used these treatments?

(If yes,) do they tell their health care provider about this? Why yes/why no?

V. PERSONAL AND FAMILY EXPERIENCE **[MOST IMPORTANT]**

- A. Who in your family is involved in helping you make health care decisions?
- B. How does your family help you manage your diabetes?

**[PROBE TESTING BLOOD GLUCOSE, EXERCISE OR PHYSICAL ACTIVITY, FOOD PLAN MODIFICATIONS]**

How does your family feel about your diabetes?

- C. Does stress play a role in the lives of people with diabetes in your community? How/why?
- D. Have there been particular challenges or problems your family has had to face since you were diagnosed with diabetes? Why yes/why no?

What have they done to cope with these problems?

- E. What kind of support does a person with diabetes need from his/her family and community?

**[PROBE CHURCH, FAMILY, AND COMMUNITY ACCEPTANCE]**

Please give me some examples of this type of support.

**VI. FOOD PLAN AND EXERCISE OR PHYSICAL ACTIVITY [IF TIME ALLOWS]**

- A. What kinds of things does diabetes keep you from doing?
- B. How have you changed your eating habits since learning you have diabetes?

**[PROBE TYPES AND PREPARATION OF FOOD]**

What has been the hardest change to make in terms of food choices?

- C. What is the hardest part about following your food plan?

For instance, a person with diabetes is invited to a social gathering. People have brought food to share. What problems does a person with diabetes have in this situation?

How do they cope?

**[PROBE FOR OTHER EXAMPLES]**

- D. Are there any particular problems with being a Native American and maintaining the food plan that your health care provider recommends for your diabetes?

**[PROBE DOES FOOD PLAN INCLUDE/ EXCLUDE ETHNIC FOODS?]**

- E. Do people with diabetes feel excluded from any physical activities? How? Why?

For example, the grandchildren of a person with diabetes want to go for a walk. The grandparent's blood sugar is high so he/she is tired and may not want to participate.

**[PROBE FOR OTHER EXAMPLES]**

- F. Does exercise and physical activity help you manage your diabetes?

Why/why not?

**VII. PROJECTIVES [IF TIME ALLOWS]**

Now I'm going to say a sentence, and I'd like you to complete it with the first word that comes to mind. Please write down the first thought that comes to your mind as I finish speaking.

**[MODERATOR WILL DISCUSS RESPONDENTS' REACTIONS AFTER EACH PROJECTIVE IS COMPLETED]**

- A. “People who have diabetes are...”
- B. “Thinking about my diabetes, if I could change one thing, I would...”
- C. “The worst thing about having diabetes is...”
- D. “The best thing about having diabetes is...”
- E. If you were going to create a manual for people like you to teach them about diabetes and how they/their family members should treat it, this manual should contain...

**[PROBE ANY PARTICULAR ETHNIC/CULTURAL COMPONENTS THAT THIS MANUAL SHOULD PORTRAY]**

- F. “What I wish my health care provider knew about Native Americans is ...”

**[MODERATOR WILL COME TO THE BACK ROOM TO SEE IF THERE ARE ANY OTHER QUESTIONS]**

## ***APPENDIX E:***

### ***BUDGETING FOR FOCUS GROUPS***

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Many factors influence the cost of a series of focus groups. “Full-service” commercial support, including a professional moderator (strongly recommended) and experts to analyze the results, typically costs at least \$5,000 per group in 1997. Approximate costs for one such focus group of 10 to 12 participants are shown in the table below.

<b>Activity</b>	<b>Approximate Cost</b>
Recruiting participants	\$1,000-\$1,500
Incentives for participants (e.g., honorarium, transportation)	\$600 (@ \$50 each for 12 people)
Space rental	\$300 per day
Refreshments (for participants only)	\$150
Professional moderator	\$800 and up depending on services provided
Taping	audio: \$25; video: \$250
Transcription	\$175 and up
Analysis of findings and report preparation	Depends on scope of services provided

There are a number of ways to reduce these costs. Ways to reduce expenses while maintaining the integrity of your research are summarized below and discussed in Section 3. Be sure you evaluate the research implications of any cost-cutting measures you consider.

When thinking about ways to cut costs, ask the following questions:

- ◆ Is a suitable conference room or other appropriate space available at no cost or at nominal cost?
- ◆ Are community partners or staff willing to donate or prepare refreshments?
- ◆ Do you have names and phone numbers of prospective participants? If you do, the cost of recruiting participants will be considerably lower.
- ◆ Do you need a verbatim transcription of the discussion, or could the detailed notes of an observer serve your purpose as well?
- ◆ Are you comfortable with the idea of preparing the report yourself? Or, if you think your study would benefit from the guidance of research consultants, do you need only a modest summary of the main themes rather than a lengthy and detailed report?

By contrast, you may need a more generous allowance if

- ◆ The people you want to recruit live far from an appropriate facility.

## *Appendix E*

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- ◆ You want to recruit health professionals and must pay them honoraria comparable to their hourly rate.
- ◆ You need a moderator who speaks a language other than English or a “simulcast” translator.
- ◆ You want professionals to prepare a detailed analysis of the findings.

Discuss your needs carefully with a focus group field firm, moderator, or other research consultant. Most will be quite willing to help you make the most of your budget and suggest ways to cut costs without sacrificing quality.